

PERCEIVED STIGMATIZATION AND COPING OF AFRICAN AMERICAN
WOMEN WITH BREAST CANCER

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Perceived Stigmatization and Coping of African American Women with Breast Cancer

Breast cancer is the most common type of cancer diagnosed in American women of all ages, and it requires complex care because it concerns a body part that has great significance for patients and their partners (Rowland & Massie, 2010). Even though women have a better understanding of breast cancer and more resources to manage their illness, it continues to be a significantly stressful process due to the plethora of factors that contribute to their decision making in regards to their treatment (Rowland & Massie, 2010). Psychosocial responses to breast cancer include: a) psychological discomfort, such as anxiety, depression, or anger; b) behavioral changes; c) marital and sexual disruption; d) body image related fears; and e) fear of recurrence or death (Meyerowitz, 1980). These responses can be influenced by several factors, including culture, ethnicity, minority status, socioeconomic status (SES), and cancer stage at diagnosis (Johnson, 1998; Peek, Sayaad, & Markwardt, 2008; Rowland & Massie, 2010).

There is significant evidence that ethnicity, culture, and SES are associated with health disparities in the treatment and outcome of cancer (Johnson, 1998). These disparities highlight the need for close examination of these aforementioned factors when discussing cancer. Johnson highlights several reasons why culture should be carefully examined. Specifically, cultural beliefs about health and illness will affect the recognition and attention to early symptoms (e.g. breast self-examination) and the patient's response to diagnosis, treatment, and adjustment to living with cancer.

African American women have the highest breast cancer death rates of all racial/ethnic groups in the U.S. (NCI, 2015) and have a 73% higher mortality rate than

white women, with a racial gap that has increased over the past decade (Hirshman, Whitman, & Ansell, 2007). There are several factors that may contribute to the development of these disparities, such as fatalistic beliefs about cancer and fear of treatment procedures (e.g. mastectomy; Peek et al., 2008), spirituality related factors, and mistrust of the medical system due to experiencing discrimination (Gullatte, Brawley, Kinney, Powe, & Mooney, 2010; Peek et al., 2008). These factors may impede African American women from early screening and treatment of breast cancer.

There are also several differences in the coping strategies of the African American women cancer patient as compared to Caucasian women. African American women tend to use more religious coping and less humor than Caucasian women (Carver, 1997; Carver, Scheier, & Weintraub, 1989), and it appears that they use spirituality in order to find hope about the future and the potential recurrence of cancer and to cope with the treatment and its side effects (Simon, Crowther, & Higginson, 2007). The reaction to the illness, the distress, and the choice of certain coping strategies is inevitably intertwined with the person's beliefs and culture (Johnson, 1998; Peek et al., 2008; Zebrack, Zevon, & Turk, 2007) and with the options patients have in terms of supportive environments (Figueiredo, Fries, & Ingram, 2004). Furthermore, cancer patients may have to deal with the associated stigma of having a life threatening illness (Holland & Weiss, 2010), which in turn may affect the way they cope (Miller & Kaiser, 2001).

Due to their illness, cancer patients may face stigmatization, such as avoidance from others, undue admiration, lack of social contact, and social isolation, which may increase their stressors (Wilson & Luker, 2006). Poor social resources or social support may affect patients' self-esteem and general distress (Heijer et al., 2012). In addition, the

side effects of cancer treatment, such as chemotherapy, may contribute to the patients' experience of stigmatization, interfere with their personal identity, and affect the way they interact with others (Rossman, 2004). Stigmatization may significantly affect the psychological adjustment of cancer patients and may contribute to the exacerbation of psychological distress through self-blame, development of poor self-esteem, anxiety, anger, depressed affect, and causal attributions (Else-Quest, LoConte, Schiller, & Shibley- Hyde, 2009). Also, the degree of stigmatization, social rejection, shame and isolation have a significant effect on patients' self-esteem and self-image (Fife & Wright, 2000).

Patients who experience stigma for their illness may withdraw socially and/or may keep their illness a secret (Link, 1987), which may in turn affect their level of social support and their coping resources (Krishnasamy, 1996). In addition, the barrier of stigma may impede cancer patients from seeking psychological help and thus affect their adjustment to their illness (Matthews, Corrigan, & Rutherford, 2003). Individuals who are stigmatized have a devalued social identity, which may affect the way they cope (Miller & Kaiser, 2001). Studying cancer through the lens of stigma may contribute to the examination of how societal factors and the context of a particular place and time may affect patients (Joachim & Acorn, 2000).

The lack of research on both stigma and coping may hinder our holistic understanding of cancer patients, specifically women with breast cancer. Thus, it is important to examine the experiences of individuals with a chronic illness by considering both variables: stigma and coping. The majority of the literature on stigma and coping with chronic illness comes from studies that either disregard cultural factors or focuses

primarily on individualistic populations and cultures. Individuals with chronic illness, such as cancer, have to live and interact in a particular societal context and hold attitudes and beliefs affected by their culture (Johnson, 1998).

Statement of the Problem and Purpose of Study

The current literature does not adequately address the impact one's culture can have on the personal experience of cancer. Cultures react differently to cancer, yet little has been written about the impact of culture on, for example, an African American female's experience of breast cancer. Prior research on African American women and breast cancer has described forms of stigma and the experience of feeling stigmatized, but it has failed to examine, in depth, patients' opinions about: a) why they feel stigmatized (what is it about the African American community that results in stigma), or b) how the experienced stigma has influenced their coping strategies. Omitting the broader social context can be misleading because it misses the fact that not every culture reacts to cancer in the same way, and some cultures may be more stigmatizing than others. It is imperative to consider the cultural context and the culture's impact on degree of stigma in order to better understand effective coping strategies in African American women.

Research Questions

- Research Question #1: What is the perceived stigmatization that African American women with breast cancer experience?
- Research Question #2: How does perceived stigmatization affect the coping strategies of African American women with breast cancer?
- Research Question # 3: What are the reasons for choosing certain coping strategies?

- Research Question #4: How does African American culture influence stigmatization and coping strategies of African American women with breast cancer?

Method

Participants

The sample for this study was comprised of 11 African American women. All participants were breast cancer survivors (stages 0-II [six participants reported being diagnosed with stage II, four with stage I, and one with stage 0]). A total of 13 women were interviewed and 11 met the inclusion criteria for participating in the study. The two women who were excluded from the analysis did not endorse any of the screening questions indicating experience of any stigmatization as a result of their illness. Participants were all between ages 34 and 62 years old, and were fluent in English. Number of years since diagnosis ranged from three to 12, with a mean of 5.9 years since diagnosis, and a mode of three years. Each of the participants completed an in-person screening and the semi-structured qualitative interview. All the participants received a \$20 gift card for their participation. All participants completed the full interview.

Per qualitative research guidelines, the number of participants is usually small because the purpose is to gain an in-depth understanding of each participant's experience (Hill, Thomson, & Nutt Williams, 1997). Hill et al. (1997) recommended 8 to 15 participants in order to have a large enough sample to determine whether findings are representative for a number of people and not only representative of one or two individuals.

Participants were recruited from (a) two not-for-profit organizations that offer help to cancer patients, (b) one cancer related event c) one cancer hospital and (d) word of mouth. Each participant who agreed to participate was given a contact form and an informed consent document. Once these forms were returned, the participant was scheduled for a time to complete the Screening Questionnaire. The Screening Questionnaire was used to recruit participants who have experienced stigmatization due to their illness. It was required that participants endorse at least one of the four screening questions to qualify for the study (see Appendix for a description of the screening questionnaire). Those who met the inclusion criteria participated in a full semi-structured qualitative interview. All participants were audio recorded.

Researchers

The research team consisted of five members: the primary investigator who is a doctoral student in Counseling Psychology, two doctoral students in counseling and school psychology, one licensed mental health counselor and one licensed counseling Psychologist. The primary investigator is a White, Greek woman with a theoretical orientation that integrates feminist, developmental, and family systems approaches. Additionally, the primary investigator has clinical experience with cancer patients. The external auditor is an African American female, counseling psychologist who works at a college counseling center. The auditor is a licensed psychologist who utilizes a systemic-psychodynamic approach in conceptualizing client issues. The role of the auditor is to examine whether the raw data (the answers of the participants) are in correct domain areas and have been represented faithfully by coders as designated core ideas. The auditor

also ensures that the wording of the core ideas captures the meaning of the material and that the cross-analysis is representative of the raw data (Hill et al., 1997).

The coding team members varied in gender and race (one African American woman, one woman from the Philippines, and one Caucasian man), age (33-45 years-old), and theoretical orientation (cognitive-behavioral, humanistic, and developmental). According to Hill et al. (2005) and Hill et al. (1997), biases often arise from demographic characteristics such as theoretical orientation, sex, and race, thus it was important to have a considerable diversity of these variables within the members of the research team.

Research team training. All the members of the research team completed the Collaborative Institutional Training Initiative (CITI) training through Ball State University. The members of the team had no prior experience with CQR; therefore, specific training was conducted (Hill et al., 2005). Research team members were asked to read Hill et al. (2005) and Hill et al. (1997) which included a detailed description of CQR, the guiding methodology. Additionally coding team members attended two training meetings. At the first meeting the primary investigator gave a detailed presentation on the theory and process behind CQR, and addressed questions. At the second meeting members of the team, along with the primary investigator, discussed personal biases related to the topic of research in order to acknowledge and be aware of biases while coding the data. Given that consensus and equality of power are important components of the CQR process (Hill et al., 2005), the research team members were also encouraged to discuss their opinions and problems openly and freely throughout the research process.

Team members' initial biases. Team members' biases surrounding African American women with breast cancer and their experiences of stigmatization as well as

their coping strategies were discussed as part of the training meeting, as suggested by Hill et al. (2005). In order to facilitate an open dialogue about personal biases the principal investigator asked each member to send, via e-mail, two to three biases that they hold for the population. Subsequently, the primary investigator created a list of the biases and discussed them with the members maintaining the anonymity of each team member. Reported biases include the following: expecting African American women to be “strong and stoic,” considering African American women as especially religious, feeling discomfort around African American women who appear to be “tough.” The principal investigator and team members discussed the origin of their biases and how they may affect them in the research process.

Procedures

Measures.

Screening questionnaire. Developed by the primary investigator, the Screening Questionnaire (see Appendix A) was used to gather demographic information and ensure that the participants meet the inclusion criteria. The Screening Questionnaire also included four screening questions about experiencing stigmatization: a) Since the time of your diagnosis did you feel that people treat you differently? b) Do/Did you ever feel uncomfortable discussing your diagnosis and/or your symptoms with family members or significant others or others in your community because you were unsure about how they would respond? c) Did you ever have the need to hide your illness from others because you were unsure about how others would respond? d) Have you ever felt some kind of stigma because of your breast cancer? Participants had to say “yes” to at least one of the screening questions in order to participate in the study.

Semi-structured qualitative interview. The semi-structured interview (see Appendix D) was developed based on a review of the literature on perceived stigmatization of patients with chronic illness (Bloom & Kessler, 1994; Chapple, Ziebland, & McPherson, 2004; Rao et al., 2009; Rossman, 2004; Wilson & Luker, 2006). Initially, each participant was prompted to share her story about her journey with breast cancer. Subsequently, each was asked to talk about her experience related to the screening question/s that she endorsed. Finally, each participant was asked to answer questions related to her experience with stigma, coping, and personal identity.

Pilot study. One pilot interview was conducted in order to examine the length and clarity of the questions, to allow the principal investigator to receive feedback from the participant about the quality of the questions, to examine the thematic relevance of the interview questions to the topic, acquire information about the data, and practice protocol questions (Hill et al. 1997; Kvale, 1996). No significant changes were necessary following the pilot interview. Thus, this interview was analyzed with the remaining interviews.

Interview procedures. The principal investigator conducted all the interviews. The interviewer's clinical experience with cancer patients was drawn upon in order to judge when to probe, how to encourage the interviewee, and what boundaries to maintain in terms of intrusiveness. As Hill et al. (1997) suggest, having one interviewer for all the interviews ensures some consistency across interviews. Conversely, having one interviewer may create some possible style and bias effects (Hill et al., 1997). It is important to note that specific characteristics of the interviewer may have affected the interview process and the dynamics between the interviewer and the participant. The fact

that the principal investigator is Greek, White, female, has a foreign accent, and has experience working as a psychotherapist with cancer patients, may make some participants more reserved because of the apparent differences between the two of them. On the other hand, it is possible that because the topic of discussion was related to stigma, they may have felt comfortable discussing this topic with someone who is not a part of their community.

The participants had to sign a consent form that allowed the principal investigator to audio record the interview. The interviewer explained confidentiality and addressed participants' questions regarding the interview process. Each participant interviewed either in a private location of her choosing or in a private room in a public agency (i.e., a public library). The interviewer explained that the purpose of the study was to explore the experiences of African American women with breast cancer and that the goal of the study was to advance general understanding of the experience of living with breast cancer. Throughout the interview, the researcher took caution not to ask questions that confirmed her beliefs about cancer related stigmatization and coping styles. After the interview, the principal investigator recorded her own thoughts, reactions, and impressions of the interview. This technique aims to increase the self-awareness of the interviewer regarding her own biases (Hill et al., 1997). Finally, the audio recordings of the interviews and any printed paperwork for the participants were stored in a locked, secure location to ensure confidentiality. After each interview was completed, the audio file was transcribed.

Transcription of the interviews. All transcriptions of interviews were conducted according to suggestions of Hill et al. (2005) and Hill et al. (1997). Undergraduate psychology students and the principal investigator transcribed each interview. The

students went through the Collaborative Institutional Training Institute (CITI training) before starting the transcription process. Interviews were transcribed verbatim in a private, quiet place where others could not overhear any conversation. When the transcription was complete, the principal investigator reviewed the transcribed interview against the taped interview to ensure accurate transcription. Once final transcriptions of all interviews were completed, the research team started the data analysis.

Data Analysis

The qualitative interviews were analyzed using consensual qualitative research (CQR; Hill et al., 2005; Hill et al., 1997). CQR involves several steps in the data analysis. These steps include developing domains, constructing core ideas, creating categories from cross-analysis, auditing the results, and checking the stability of the findings (Hill et al., 2005; Hill et al., 1997).

Developing domains. The first step in coding data according to CQR guidelines is to develop domains (topics used to group the data) through reviews of the transcribed interviews (Hill et al., 1997). There are two ways of developing domains: one way is to start with a “start list” of domains derived from the literature or interview questions, which are applied to the data and are modified according to the answers; the second way is to develop the domains from the data (Hill et al., 2005). The latter method was used in this study and the interviews were coded line by line. Although both methods are acceptable, the latter method is recommended because it asks researchers to examine the data instead of depending on preconceived ideas (Hill et al., 2005). Initially each member of the coding team had to read an individual transcript and assign each block of data to a domain (Hill et al., 1997). When each member of the coding team completed this part of

the analysis, the team met as a whole, came to a consensus about the most appropriate domains for the data, created a document including the raw data, and then decided on domain titles (Hill et al., 1997). Once the domains were completed for each transcript, core ideas were constructed.

Core ideas. Next in the coding process, the team constructed core ideas. The overall coding process aims to summarize the data in fewer words than that of the transcription (Hill et al., 2005). However, it is important to note that these “summaries” represent shorter versions of the transcription without making assumptions, interpretations, or straying far from the data (Hill et al., 2005), while at the same time are part of the broader domain (Hill et al., 1997). Team members constructed core ideas based on the data individually, and then discussed their suggestions as a team until they came to a consensus. When the core ideas were completed, members conducted the cross-analysis.

Cross-analysis. Cross-analysis is an important part of CQR, during which team members examined, and reported similarities between transcripts, as suggested by Hill et al., 2005. All team members had to reach a consensus for categorizing a certain quote on a particular domain and a specific core idea. Further in cross-analysis the coding team identified similarities across transcripts. Finally, the external auditor provided feedback for the domains, core ideas, and cross-analysis.

Auditing the results. All procedures were in accordance with Hill et al. (2005) and Hill et al. (1997). The external auditor examined whether the data (from the transcribed interviews) was in the correct domains, if the core ideas represented all the information contained in the raw data, and if the cross-analysis represented the data in an

accurate way. The auditor also provided feedback to the team regarding the analysis, which was later received and integrated by the coding team. Subsequently, the auditor reviewed the final analysis of the team. Although the auditor was considered part of the team, she was not involved in most of the team meetings and as a result, was less exposed and vulnerable to any “groupthink.”

Criteria for Evaluating CQR

As suggested by Hill et al. (2005), once the auditor reviewed the cross-analyses and the team made the necessary changes, the entire analysis process was evaluated based on the three criteria. These criteria included representativeness of the sample, trustworthiness of the method, and coherence of the results (Hill et al., 1997). The first criteria, representativeness of the results, is evaluated through the labels of “general,” “typical,” or “variant,” which were assigned to each category based on frequency (Hill et al., 2005; Hill et al., 1997). These labels are defined as follows: general - a category reported by all or all but one participants, typical - a category reported by more than half but less than general, and variant - a category reported by at least two cases but less than typical. The second criteria, trustworthiness of the method, was achieved through a consensual process of data analyses, open discussion of biases, and frequent dialogue regarding the CQR process (Hill et al., 1997). The final criteria, coherence of the results, refers to the idea that results should make logical sense to a reader, account for all the data, answer the research questions, and is presented so that a reader can understand how the research team came to their conclusions (Hill et al., 1997). Coherence was ensured through answering the research questions in a logical way along with supporting the findings with direct quotes from the participants to further illustrate categories within

each domain. In this study, coherence was shown through answering the research questions in a logical way that accounts for all of the participant data (Hill et al., 1997).

Results

According to Hill et al.'s (1997) guidelines for CQR, domains and core ideas were classified as *general* if all or nearly all participants indicated endorsement of a core idea, *typical* if 50% or more endorsed the core idea, or *variant* if less than half but at least two participants endorsed the category. In this study, general ideas were classified as categories that were endorsed by a minimum of 10 participants, typical were the categories that were endorsed by a minimum of six participants, and variant the categories that were endorsed by at least two participants.

General and typical core ideas are summarized with examples of quotes below, including a discussion of the variant ideas. Also, it is important to note that for coherence purposes the presented findings were organized based on the broader themes explored in this study. Coherence refers to the logical presentation of the findings, in relation to the research questions (Hill et al. 1997). Thus, the analyzed data were organized by the author, for clarity, in the following broader themes: (a) sense of self and personal experiences, (b) experiences of stigmatization, and (c) coping strategies.

Table 1

Sense of Self & Personal Experiences

Domain	Core idea	Frequency
Identity	Perception of self	Typical (7)
	Shifting roles/asking for help	Typical (7)

	New identity	Typical (7)
Biological changes	Awareness of body changes	General (10)
	Acceptance of changes	Typical (6)
Mortality	Awareness of mortality	Variant (5)
	Unfinished business	Variant (2)

Identity

The domain of identity contained three core ideas, and each one of them was endorsed at a frequency that indicates each are typical core ideas. The first core idea, *perceptions of self*, endorsed by seven participants, contains statements that indicate a strong sense of self, and of personal characteristics and roles that survivors have about themselves. The quotes of this category reveal how survivors see themselves and portray a picture of women who are strong, independent, resilient and overall, of women who have a positive sense of self-worth.

Figure 1. Sample Quotes About Identity: Perceptions of Self

Participant 6	“Being independent, very self-sufficient, always caring for myself, that part of having to reach out and say hey, I need someone to cook me a meal because I can’t lift anything over 5 pounds.”
Participant 9	“I am strong, I am [a] leader, I am compassionate.”
Participant 1	“I’ve always been a very hard worker. And before I left here I had 3 jobs. You know, I worked here 26-27 years. Did hair for 25 years... Retail clothes... I’ve worked all my life and also at my church I was a singer. I’ve been a singer, a director, worshiper, and now I come back home and I don’t get to do anything. I am not doing anything...when you leave from that treatment you feel pretty good. Uh, how I was going to be feeling I was thinking hard now that I don’t have this to do anymore. And so, that was a weird thing. Uh, I said, I said to myself, I almost don’t want it to end. It had become my life, kind of. But that was not a good thing to say (laughs)...That was hard for me because I’ve always been a nurturing, loving person to people. So I’ll meet strangers I always greet

	people with hugs, at least a hug, not everyone with a kiss but most people with a hug, and so not being able to hug people..."
Participant 3	"I didn't have control over it. You know, that was the biggest thing, I was always in control of situations and that was something just like being in an airplane. You know, you get up there in the air, and once you up there, you lose all control... you can't tell the pilot, you know, let you off ...It was just like I had lost that control that I was used to having and I didn't know how to handle it."
Participant 2	"And, you know, everyone is like- I'm really like the- I'm the joker of the family. I'm the comedian, I am the one that if they having a bad day they call me, "Tell me a joke."

The second core idea, *shifting roles/asking for help*, endorsed by seven participants, contains statements that indicate the transition in the roles of participants. Specifically, the majority of participants reported having to reevaluate aspects of their identity, understanding that their abilities in certain areas changed and they had to shift roles from being caretakers to receiving help from others. Participants talked about being significantly impacted by this shift in their role, and initially resisting the idea of asking for help, but eventually realizing that they need to reach out to others in order to take care of themselves or their families.

Figure 2. Sample Quotes About Identity: Shifting Roles/Asking for Help

Participant 2	"And at first I was very overwhelmed because I'm the care taker, I'm used to taking care of people, I am used to being the one that people come up to me and say, "Help me, I'm going through such and such." And now it was my turn. And I didn't take it too well."
Participant 10	"I had to be broken as my church people said. They said that "we are here to help you and that is what we will do whether you like it or not." I did not like the people coming to my home or not be able to take care of myself. I felt I had to be broken. Once I felt that it was all for good and they were there to help me I was fine."
Participant 8	"(after the cancer)...I did realize though that no man is an island and you cannot do everything on your own and I do reach out when it is

	necessary.”
Participant 3	“But uh I was tired, I was tired and I was... I couldn’t do the things that I used to do. You know, it was just like I didn’t have the energy. Uh I couldn’t make up... I could make up my bed but I couldn’t clean up my room. You know, because I didn’t have no energy. I couldn’t just clean up so you know, my daughter, she did mostly everything anyway of my kids. But um, it was just, it was just really, it was tough and I’ve always been the type of person that clean up and you know, like to do things on my own and, it just took a lot out of me.”
Participant 6	“Right and then even when it came to the care of my daughter, I couldn’t drive. Um, I remember one time she missed her bus and I’m like I can’t drive you to school. So, I had to go next door to my neighbor, knock on the door, wake her up, and ask her if she could take my daughter to school. That was very hard for me to do. You know, because here I was. I looked like you know what. No makeup, I’m in my robe. You know, it’s just...let me go over here so she can get to school on time and um, that was a little challenging.”

The third core idea, **new identity**, endorsed by seven participants, contains statements that indicate a change in the values and view of self. The majority of participants talked about having a deeper understanding of who they are by accepting their diagnosis as part of their identity and making changes in their lives that allowed them to be more true to their needs. In other words, in this category we see the growth of participants during their journey of surviving breast cancer.

Figure 3. Sample Quotes About Identity: New Identity

Participant 2	“You know so, one good thing about having cancer is you meet a whole new family. You find whole new friends. You um you find yourself. You find the real you, you-you dig down real deep and say, “This is who I am.” It’s no more um me, cancer is a community, it a part of you know you know you say, “Oh, you know, I’m a breast cancer survivor.”
Participant 8	“I became a stronger person, you start appreciating life more instantly. You have a different thought process about dying. And yes you want to, I am more bold..., I feel like whatever the goals are that I have I will pursue them and do them. In 2007 after

	doctor said that I made it through the survival therapy, I thought now I need to do some things I wanted to do in all my life, which is to go back to school. And I just put my feet in there, full time student, full time employee, full time volunteer.”
Participant 10	“It made me bolder and If anything difficult came up I was like, you went through chemo, through surgery, you can do this. It has boosted me up, changed my way of what I eat and the company that I keep. I want to be around positive people and it also made me reexamine myself and see that I can’t help everybody.”
Participant 12	“I became this person who laughs. People will notice I am in the room because of my laugh. Cancer made me to not see things as serious, and to laugh and believe and just know that God is able.”
Participant 5	“And like I said when I was actually diagnosed, I was in-between jobs, I was just working this little temporary job. Um so after my... what I went through, started with the radiation, I actually started working a temporary job again. It was a legal job, I was doing kind of track reviews, which was fine. But I really kinda just through my experience, I had decided I didn’t really want to go back to, I definitely didn’t want to go back to practicing law, I didn’t even necessarily want a job involving law. I just felt like I really needed to do something that was more people oriented and where I kinda could give back to the community and to people.”

Biological Changes

The domain of biological changes contained two core ideas. The first core idea, *awareness of body changes*, was the most frequently represented category endorsed by 10 participants, and is thus a general core idea. The quotes of this category indicate the experience of women while observing the changes in their body, such as physical pain, discomfort, scars, loss of hair etc. In addition, this category focuses on the adverse side effects of treatments, and shows the way that women processed these changes.

Figure 4. Sample of Quotes About Biological Changes: Awareness of Body Changes

Participant 10	“Yeah I had scars, I m very conscious of my looks. It was a time I lost a lot of weight and I had to buy different size of cloths. And people were like what does she have? She is losing all this weight,
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	what if she has something else ...it also changes your body, I have more allergies, or I had the flu, I never had it before.”
Participant 9	“The chemotherapy, the medicine was horrible, the smell. Chemo sometimes was good but sometimes made my stomach upset...The change that I noticed is that I have to sleep on my back, but other than that it is alright. Even when I lost my hair I thought it was just hair it will come back ... I tried to push myself initially to go to work but my body would not allow it so I accepted it and stayed at home more.”
Participant 8	“After my breast was removed they put the implant... When I put the implant in I had a problem with it, it deflated and but even before that you had to go through the dressing process, and it was then when I had to see what I look like and that made me you know.”
Participant 6	“Initially, because I had those darn tissue expanders in, I didn’t want people to hug me because they were like bricks. Those things were literally like bricks. I wouldn’t hold children...babies, I refused to hold, um, because I was.. I wasn’t afraid that they would do any damage to me because, I figured, you can’t damage me. There’s nothing here to damage anymore.”
Participant 1	“I don’t feel good about my body because I just really let it go...And it hurts, it physically hurts to touch it. It hurts to move my body. It takes a lot of energy...I’m still, you know, fighting this battle in my mind...After the fourth treatment I started losing my finger, feelings in my fingers, my feet, all my finger nails turned black, all my toe nails turned black. And I still have neuropathy I guess.”

The second core idea, *acceptance of changes*, was endorsed by six participants, thus is categorized as typical. Participants in this category talked about developing comfort with the visible changes they experienced in their body, whether it was losing their hair or a visible change of their breast size. Specifically, in this core idea participants’ quotes indicated almost celebrating the changes in their body by choosing not to hide them or alter them.

Figure 5. Sample of Quotes About Biological Changes: Acceptance of Changes

Participant 3	“So to me, hair doesn’t really make a person and you know...I finally got to the point where I would wear my hair...head bald because I wasn’t afraid...(thinking back) No I’m beginning to feel more comfortable with my body and I’m looking forward to having, you know, my surgery um next month. I’m looking forward for the outcome.”
Participant 12	“I just didn’t want to lose my hair. My dad used to say my hair is my glory, and I thought now I’ll have to wear a wig. But people were positive, they knew and would be like ‘this is cute.’ Nobody downed me...one day I took my wig off and they laughed and we all laughed.”
Participant 8	“They were like maybe they will be asymmetrical, do you want to put an implant on the other side? And I was no, this side has all its working pieces so I only want to work with this side that was affected.”
Participant 2	“She said, ‘Somebody read your chart wrong. And that’s what happened to your breasts. We gave you too much hormone. So we aren’t going to give you that much. We are going to give you a little bit of testosterone and some estrogen and progesterone. We are going to do that.’ And I said ok. So about six months after that I was diagnosed with breast cancer... I needed to go get a wig and you know, we went wig shopping. She bought me two... I think I bought three and uh, after I got them wigs...”

Mortality

Mortality was another domain that emerged from the answers of the participants.

Awareness of mortality was endorsed by 5 participants and thus categorized as variant in this domain. Participants in this domain expressed the change in their awareness about their own death after they were diagnosed with breast cancer, and the connection between the cancer diagnosis and dying. One quotation example in this category was:

Everybody is going to die one day. So, I’m – you know – I’m just doing the best I can to stay here...I think a lot about death now. I used to didn’t worry about it. I used to worry about death but now I’ve accepted it. If I die, I die. I was put here to die. I used to worry about oh Lord one day I’m going to die, I’m scared of dying!

Another quotation example in this category was:

Mentally it has been hard for me. Uh, it's hard for me to accept it because uh, like I said being diagnosed with cancer a lot of times in some cases a disease that will take you out and kill you. So, I think of it in relation to something like AIDS. And my growing up, when I think about it now, there has been somebody within a radius of 5 miles where I lived, somebody in every block has had cancer and died from it.

The second variant category that emerged was about *unfinished business*. Two participants indicated a fear of dying before they are able to fulfill their goals/wishes, and a fear of leaving their families behind before they are able to do the things they would like to do with them. An example of a quote in this category is, "I mean that's the first thing- I thought about my family. I thought about- oh my goodness-I haven't done anything I wanted to do."

Table 2

Experiences of Stigmatization

Domain	Core idea	Frequency
Changes in relationships	Changes in others' attitudes	Typical (6)
	Dissolution of relationships	Variant (4)
	Dealing with disappointment/ lack of support	Variant (4)
Perceptions of the disease	Fatality	Variant (4)
	Myths/misconceptions	Variant (3)
	Contagiousness	Variant (3)

Issues of culture	Socioeconomic issues	Variant (4)
	Racial discrimination	Variant (3)

Changes in Relationships

The domain *changes in relationships* contained three core ideas. The first core idea, *changes in others' attitudes*, was the most represented category of this domain and six participants endorsed it and is thus categorized as typical. The quotes of this category portray the reactions participants had from their family or close friends after their diagnosis. Participants described the attitude of others changing in a way that dismissed their abilities and focused only on their illness. Participants in this category emphasized how they were only seen as being “sick” and how others started feeling uncomfortable around them.

Figure 6. Sample of Quotes About Changes in Relationships: Changes in Others'

Attitudes

Participant 2	“And when she found out I had cancer... she said that she couldn't stand to see me going through that so she had to get herself away from me because she couldn't stand the fact that what I was getting ready to go through...People eventually started looking at you different like ‘she's sick.’ You know, that's what they say, ‘she's sick.’ ‘Oh don't do that honey, you're sick.’ Or, ‘Are you feeling alright today?’”
Participant 5	“I would have family members and friends kinda question, Well ya know, ‘do you think you ought to do that’, or ‘don't you think you ought to rest’, or...I mean even something as simple as I'm gonna go you know pick up something, ‘Oh that might be a little heavy, oh don't do that.’ ...And that's why I think people, I always feel like people kinda make that distinction, like pre-cancer (survivor's name) and post-cancer (survivor's name). I don't know why...”
Participant 3	“They were just scared of you. They didn't know how to react to you. You know, you have cancer. They don't know how to react or they don't know what to say. They don't know how to treat you or you know, basically you just need somebody to talk to or a friend.”

Participant 7	“Um, my family they still come over. They kinda, I wanna say smother me a little bit. Its like they treat me like I'm sick. And I'll be like, I'm not. I can still do normal stuff, but they don't see it like that. So, its different. They treat you different...”
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The second core idea that emerged was *dissolution of relationships*, and was endorsed by four participants, and thus a variant. In this category participants described how their romantic or friendship relationships ended because their friends or partners were unable to understand their experiences, and did not want to see them changing because of their illness. One participant reported:

She said, ‘I can talk to you and I’ll be there if you need me, but as far as you and me going out and hanging together...’ and I said, Well my going out days are over with right now. I said I can’t, I’m sick. And she said, ‘That’s what I’m saying, you’re sick, you can’t do what you used to do so we have nothing in common.’ ... And I said, You was my friend. I lost my friend because I got cancer. You cannot see that? And then I had to figure out for myself that was her ignorance.

Another participant reported:

It was hard on him he has this thing he is very positive and that you are beautiful, I don’t want to see you suffer. He tried his best to talk me to take a different route and do natural treatments and I would not and that was a deal breaker for him and the relationship resolved.

The third core idea that emerged was *dealing with disappointment/lack of support*. In this category, which was endorsed by four participants (variant), women talked about having a hard time to reach out to others (more specifically to their family

members or co-workers), and feeling disappointed because their family members did not offer their help. In other words, in this category participants show the importance of having people around them that offer their support without them having to ask for it. One member stated:

And when I have ask for things and people don't meet that expectation it is a disappoint so to avoid that...it is hard to reach out and as...They were afraid and my son he avoided me (her children). I don't know what has happened over the years and if the diagnosis has affected him but he has been avoiding me.

Another member reported:

Family, I feel like uh, (laugh) well my family is who they are, my kids are who they are. But it would, it would have made me feel better to uh, see their face. Even if 5 minutes to come over, you know, once a week. (If they said) 'Mom you need anything.' You know, my daughter is a great cook. Great cook didn't come over and offer one meal or anything.

Another member said, "In my job I used to pick up the things more quickly, so people were saying a lot of things and then ask me 'didn't you pick that up?' People lack sensitivity in the work environment."

Perceptions of the Disease

Three core ideas emerged at the domain perceptions of the disease. All the core ideas that emerged were variant. *Fatality* was the most commonly endorsed variant category. Participants here talk about the meaning of cancer in their community and how the news of cancer is perceived as a death sentence. One participant reported: "Most people think cancer is death." Another participant said, "I just felt like my mother, you

know, was kind of like they are already burying you because they think with cancer you gonna die automatically, which is not...you know... all sickness does not lead on to death.”

The second core idea of this domain was *contagiousness*. Participants here described how they felt that other people started avoiding them because of fear of being contagious. One participant reported:

I think people actually thought that they could catch it. You know, and that's so strange. I mean, they really did. I just felt like people thought that, you know, they could catch it just to you know, hug me or anything like that and they just didn't know what to do.

Another participant said, “Or you'll get people that kinda don't wanna be by you. And I'd be like, you're not gonna get cancer. Its not contagious like that...”

The third core idea of this domain that emerged was *myths and misconceptions*. In this category women talked about their preconceptions about cancer and how the possibility of being diagnosed with cancer was something that did not cross their mind. One woman talked about how she used to believe that as a Black woman she is not susceptible to breast cancer because she associated breast cancer with White women. Specifically she stated, “Growing up we always heard and knew of white women that would have breast implants but not black women. So, you associate kind of breast cancer with breast implants with white women.”

Another participant stated:

I never even examined my breast you know, because I just felt, I guess it was just...I never had it in my mind. I never thought about it and never thought that it would happen to me anyway so uh, it was just blocked out.

Issues of Culture

Two variant core ideas emerged within the domain issues of culture. Three participants endorsed *racial discrimination*. Here participants described their experience of being discriminated because of their race from society structures, including their work environment, or the medical system. Participants reported feeling that they were treated differently, and receiving less attention to their needs as compared to Caucasian women diagnosed with cancer. One participant stated, “My co-worker came down, she was diagnosed with cancer and had a totally different approach. She was treated differently, she was a Caucasian female and she was treated differently and I tried to wrap myself around it.”

Another participant reported:

Say I was Caucasian. Its seems to me that they are treated, even by the medical field, they are jumped on quicker, they are more to get- more adept to get better attention. Their diagnosis, they get diagnosis this day they are getting worked on. You know...it's like society is saying, ‘Well, we're gonna hold off and see if your breast cancer progresses.’ Then a Caucasian woman is more like, ‘You need to get in here, and you need to get in here now. We are gonna get this- we are going to find out right now.’ It's like they are given better choices... Well with the white woman they tell her, you know, they go more into depth to what is going on with their body. They come to us-we don't understand a lot- speak to me in

layman's terms! Talk to me like you talk to your three year old. Tell me what going on with my body and then in those words right there I need to hear. I don't need to hear big long terms and things I don't know.

Another variant core idea of the cultural issues domain was *socioeconomic issues*.

Participants in this category talked about having less access to health insurance.

Specifically they indicated how the lack of insurance had an impact on the time of their diagnosis or the treatment they had access to. One participant said, "(talking about the doctors)... 'Now, what kind of insurance do you have?' You know, and that's what it's about, it's about money, its about the nature of money, it's all about money."

Another participant stated, "Uh, one thought would be maybe financially we wouldn't have insurance to cover everything because it's very expensive. That's the main thing that comes to my mind."

An additional participant example is:

Um I was working a temporary job, I wasn't insured. And my husband had been laid off as well so neither one of us had insurance and we had three children. Um and so when I found this lump under my arm, I didn't immediately do anything about it. Um I chose not to you know go to the doctor cause I kinda view that as an unnecessary expense at the time, it just wasn't all that important.

Table 3

Coping Strategies

Domain	Core idea	Frequency
Ways of coping	Positive thinking	Typical (8)

	Use of faith	General (10)
	Maintaining control despite illness	Typical (6)
	Withdrawal and isolation	Variant (4)
	Humor	Variant (4)
Disease management	Education/advocacy	Typical (8)
	Lifestyle changes	Variant (3)
Social support	Family	Typical (7)
	Sense of community/cancer survivor community	Variant (5)
	Support group	Variant (3)
	Expectations for support	Variant (5)
Processing diagnosis	Reaction to diagnosis	Variant (4)
	Accepting the diagnosis	Variant (4)
	Finding answers	Variant (3)

Ways of coping

Six core ideas emerged within the ways of coping domain. A typical core idea, 8 participants endorsed the category of *positive thinking*. In this category participants described the importance on having a positive attitude, having hope about their survival and not allowing negative comments to affect them by actively rejecting any kind of negative thoughts that came either from other people or from their own thinking. In addition, in this category there is an emphasis on fighting against the stigmatization of their illness by endorsing positive thinking, and focusing on things that feel assuring and fueling of their sense of survival.

Figure 7. Sample of Quotes about Positive Thinking

Participant 2	“And the way I cope with the stigma, was like the negative, I pushed to the back and the positive I pulled it out to the front and that’s what I fed on. Negative I pushed to the back ...”
Participant 1	<p>“The comments they were hurtful and I had to push myself with my inner motivation that it will be ok, but if I focused on what they said I would not be here today...I tell people I am survivor and I am a warrior...”</p> <p>“I’ve gone through it just being a positive person...I felt like my appearance because my thinking was positive, that’s the way my mother raised us, to take care of ourselves, don’t look like you are going through anything, if you are going through something. I felt good about my appearance.”</p>
Participant 6	“But I think, you know, maintaining a positive attitude was a thing that I think kept me going...when you’re going through it, you...you have to have a positive attitude. You have to think of terms of survival. Um, you can’t let anything negative enter into your...your mind, your spirit, or soul because when you allow negativity to come in, you begin to doubt yourself.”
Participant 9	“I think with me having a positive attitude others could see that I was ok.”

Use of faith, was the category with the highest frequency, endorsed by 10 participants and thus a general core idea. In this category, participants talked about using prayer to God as a way of developing hope about the future and connecting with a higher power. It appears from the quotes of this category that participants, through prayer develop a sense of companionship, a sense of not being alone. In addition, it appears that through praying they let go of control, and give that sense of control to a higher power.

Figure 8: Sample of Quotes About Use of Faith

Participant 2	“What I do is, if somebody comes up to me in a negative way I tell them, look, is like this. Only God knows what is going to happen to me, only God knows my future....Pray. Honey all you can do is pray. You pray so much you just pray, pray, pray.”
Participant 8	“I do not have a church home but lord knows my heart. I don’t go to

	church but used a lot of prayer.”
Participant 5	“I believe that you know I would make it through the treatment and I meant that God would heal me through the doctors and the medical treatment that I was having and so...”
Participant 10	“Spiritually, I did a lot of reading and praying, occupied my mind with other activities...”
Participant 12	“Oh they know that God heals everything cancer is a disease but God is able to heal you one way or another, on earth through the doctors or on Heaven. The God was going to heal me, I didn’t know how but he even gave me comfort when I was reading, I did morning meditation and I read a scripture in the bible that “this will not resolve in your death” and that gave me comfort. So religion played an important part. I was reading the bible and meditating and God spoke to me and that is what everyone encouraged me to do...I prayed and read my bible that was pretty much it. My religion and relationship with God...Cancer is just a disease and prayer is the key...God is first.”

Six participants endorsed the typical core idea *Maintaining Control despite Illness*. The participants here talked about the importance of having a sense of control over their bodies and who they are during the course of their illness. Specifically, participants here emphasized how they felt empowered by having a choice in their decision-making regarding their treatment approach, their decision to work, or their appearance.

Figure 9: Sample of Quotes About Maintaining Control Despite Illness

Participant 10	“Sometimes I would say I don’t want to do it today and they were understanding of that...I went back to my primary doctor and told him that I want you to find me another surgeon because this one is pressuring me to do a mastectomy but I prefer a lumpectomy.”
Participant 2	“And you’re not going to be able to work, I worked. I-my FMLA people called me and said, ‘So it says here that you have cancer and you are going through chemo and you are supposed to take FMLA, when are you going to start your treatments?’ I said, I’m almost done. And they were like, ‘Wait a minute, you haven’t taken time off?’ Nope, I’m working And that lady said, ‘You know what honey, my heart is off to you.’ I said, No. They told me I was going to be sick, they told me, and I

	was but, Katerina, I pushed myself...Cause I advise anyone that is going through chemo, any Black African American lady that has hair: cut it. Cut it off! Cut it! Don't let Chemo take it! Have some control I wanted to have the control, you know, I was not going to let chemo control-my cancer control- who I am."
Participant 8	"I never had any fear I just knew it was something I had to handle and I couldn't show any type of fear to my children because that was something they had to deal with...during the treatment no changes just work as usual no changes...to be strong, through having people, friends, family, around you and not have pity party not asking questions like 'why me' I had to go through it as a single person and a lot of women have to do that. If you need help ask for it."

Four participants endorsed the variant core idea ***withdrawal/isolation***. Participants in this category talked about disengaging from interactions with people that were perceived as negative or stigmatizing, as a way to protect themselves.

An example of a quote from this category is the following: "I don't let myself get too stressed, when something get overwhelming for me, I pull away from something, I back away. I completely shut down. You are not going to take me there, I'm not going to go there, I'm not going to argue. I will shut down because stress is a big, big part of cancer."

Humor was another variant category that emerged in this domain. Participants in this category talked about using humor as a way to cope with the changes in their body and with uncomfortable reactions from other people. An example of a quote from this category is the following: "I'd just make comments like that or, you know, you might end up breaking your ribs if you bump into my chest cause they...my breasts are hard as bricks."

Disease Management

Disease management was another domain that emerged from the answers of the participants. *Education/advocacy* was the category with the highest frequency (typical--endorsed by eight participants) of the management domain. Participants in this category talked about their need to help other women through sharing their own experience and through educating them about cancer related concerns. In this category, participants talked about their way of disseminating the knowledge they acquired through their treatment process, by being involved in organizations that have a helping cause, or by talking to other patients on an individual level.

Figure 10: Sample of quotes about Coping Disease Management: Education/Advocacy

Participant 2	“You know, people have questions, people ask questions. A lot of people will say that is a dumb question...A question that is not asked is a dumb question. So ask me anything and I’ll put it out there, I put it out there. I told people, If you want to know anything about breast cancer, anything, ask me. You got doubt, you got a feeling, you got a little ‘mmm’ in the back of your mind, talk to me I will tell you. I’m not going to sugar coat it, I’m not the doctor, I’m not going to diagnose you. But honey you bet me I’m gonna get you through it.”
Participant 5	“Well I know, in fact I really do think part of it what I went through but also part of it is because of my kinda new desire to make sure that people know things, know things about breast cancer or know what my experience has been cause it might help them. Or know you know what I think are important messages about... I coordinate people getting mammograms and pap-smears; I do a lot of education. Um I do quite a bit of case management in terms of getting, making sure people get not just their screening, but anything else that’s needed through out that continuum of care.”
Participant 10	“After the journey I am an advocate and spokesperson for people. People call me and ask me questions after their diagnosis. That also helps me cope, to help somebody else...”
Participant 9	“After the diagnosis I thought more about how I can share my experience and try to help. I’ve always had a strong connection to people but through my experience I want people to realize life is shorter than they think and to not take everything for granted. I share the experience with people.”

Participant 3	“I was able to share my story and I was able to tell them, you know, yeah it was breast cancer and you know...I’m taking chemo and you better check your breasts. You know, I was thirty-nine years old when I was diagnosed. So you know, I was pretty young... I’m able to talk to others, I have people that call me that’s getting ready to walk this journey. You know, I’m able to give them the support that they, that they need and that is really what helps me through...I was able to share and it actually made more people aware.”
Participant 8	“I felt very connected I do reach out to other cancer organizations, I participate to their fund drives, try to help the word out, how supportive others can be to help us eradicate breast cancer... Now I am a Red Cross volunteer... so doing things like that, helping people and the community.”

The second category that emerged in the disease management domain was ***lifestyle changes***. Three participants endorsed this variant category and emphasized the changes they had to make in lifestyle choices and more specifically in food. Participants here described how they shifted their attitude toward prioritizing self-care and choosing carefully their food in order to have a diet that adhered to the treatment recommendations. An example of a quote from this category is the following:

In my lifestyle I had to focus on trying to focus on trying to eat because food and smell you just don’t want to eat. My stomach is totally different now. I try to enjoy life the best I can. I went to a brand new job but I had to leave because it was too stressful, so I had to prioritize self-care.

Social support

The most highly endorsed typical core idea of this domain was ***family***. In this category participants described the importance of having family members being available

in order to help them, and specifically, having around family members who have an attitude that communicates strength and deep caring for them.

Figure 11: Sample of quotes about Social Support: Family

Participant 7	“When I was first diagnosed but I do have a strong family and friend support system. So, it kinda made it easier. Like I had a lot of people go to the doctor with me.”
Participant 2	“I said, I just want to know if I look like a man or not. He (the partner) said, ‘You are always going to be beautiful to me.’ And my other son, my middle son, he took it real bad. He just, he did a complete 360 degrees, everything changed around. He went and bought me jewelry, he bought me this-I wear it all the time- I haven’t took it off since the day of my diagnosis-he went out and bought me this- it was a bracelet he had on. He went and made it into a charm necklace for me and I put it on...I did I had so much support...”
Participant 8	“But my daughter was a real trouper she came here right away, flew here and stayed 6 weeks and stayed through the surgery...”
Participant 4	“When I got sick I had to ask my mom to come over. And of course she was running up the road trying to get over there. And then I told her I was doing okay and she didn’t need to come over. And I was just, she was freaking’ out because I was here by myself and my husband was at work and she’s a nervous wreck. (Laughs) Mom I’m okay. I’m fine you know. I was able to get around and do what I needed to do. But, when I got sick that time, I needed her to be there.”
Participant 5	(Talking about her daughter) “You know she would come in my room and just climb in the bed and lay in bed with me sometimes.”

Sense of community/cancer survivor community was another category (variant) that emerged in this domain and was endorsed by five participants. In this category, participants talked about the importance of the help they received from different cancer related organizations. Specifically, they emphasized the importance of having other women, who have knowledge and experience in supporting cancer survivors, offering

either instrumental help or emotional support, without them having to ask for it. An example of a quote is the following:

People brought food, people gave money, people gave I mean listened to me, they were sympathetic to me, they were like, ‘Anything, anything you need, anybody to talk to.’ People would call me, ‘How are you sleeping? Are you doing alright?’ I had so many different women groups call me...It’s no more me, cancer is a community, it is a part of you know, oh, you know, I’m a breast cancer survivor.

Another variant core idea emerged in this domain, was *support group*. In this category, participants talked about the positive role that support groups –specifically friends, played. They talked about having friends that they felt comfortable enough to ask for help. An example of a quote in this category is the following:

You know I could call them and say, hey, can you fix something for everybody else to eat? You know and they would just come over and get in the kitchen and start cooking. And that was company for me too. Or um I had a friend who thinks cleaning is therapeutic...

Another variant category that emerged in this domain was *expectations for support*. In this category participants talked about the lack of mental-emotional support from people or society structures. An example of a quote is the following:

My husband, he says all the time, ‘well I supported you when you...’ No. I mean you were there but the mental support wasn’t there. So it’s totally different than you know, you supporting a person, you know, when they going through treatment and you know, you might take them to treatment or something like that but that mental support.

Another example of a quote is the following: “There were not enough programs for African American women out there but it is getting better now.”

Processing diagnosis

Three variant core ideas emerged in the domain processing diagnosis. The first core idea that emerged was *reaction to diagnosis*. In this category participants talked about the initial reaction, the difficulty in accepting the fact that they had cancer, and their effort to understand the reason for having cancer. An example of a quote of this category is the following:

I said it in my mind but I did not believe it...I just sat there and I was afraid because even though I did early prevention I felt ‘why me?’ I never smoke or drink, I eat healthy, I love to exercise so I thought ‘why me’, I was fearful.

The second core idea that emerged in this domain was *accepting the diagnosis*. In this category participants talked about the process of coming to accept the fact that they have cancer. Specifically, they talked about how certain events, like the end of their chemo treatment, or the changes in their appearance helped them realize that they have cancer. An example of a quote is the following:

And never actually, I never cried about ‘I got cancer.’ I guess because I never believed it. In my mind I just never brought myself to believe it, until my last treatment. And after your last treatment of Chemo there is a bell that you are supposed to ring to let everyone know that you’ve come through and you’re done with everything. And until I rung that bell at the last treatment I had; when I rung

that bell it hit me ‘I had cancer.’ (laughs). That was the first time I was able to say I had cancer.

Finally, the last category that emerged in this domain was *finding answers*. In this category participants talked about the importance of having a supportive network that allows them to understand the changes they have to go through because of their treatment. Also in this category participants emphasized the significance of being well informed about the disease and having answers to their questions. An example of a participant quote is the following:

“There was a doctor at the follow up of the treatment, there is a doctor that does not understand the experience and I almost dropped from her. It is important to get to the root of the problem and not just stay at the surface of it. I need an explanation about medication... maybe I would ask the doctors about if there is someone who can explain what is going on and what to expect.”

Summary of Results

From the data analysis, ten domains emerged. Thirty of the core ideas related to the experiences of perceived stigmatization and coping of African American women survivors of breast cancer. The domains included: 1) Identity, 2) Biological changes, 3) Mortality 4) Changes in relationships, 5) Perceptions about the disease, 6) Issues of Culture, 7) Ways of Coping, 8) Disease Management, 9) Social Support, and 10) Processing Diagnosis. While none of the domains contained subcategories, each contained multiple core ideas. The first domain, identity, contained three core ideas: perceptions of self, shifting of roles or asking for help, and new identity. The second domain, biological changes, contained two core ideas: awareness of body changes, and acceptance of changes. The third domain, death, contained two core ideas: awareness of mortality, and unfinished business. The fourth domain, changes in relationships,

contained three core ideas: changes in other's attitudes, dissolution of relationships, and dealing with disappointment, wishes or lack of support. The fifth domain, perceptions of the disease, contained three core ideas: contagiousness, myths and misconceptions, and death. The sixth domain, issues of culture, contained two core ideas: racial discrimination, and socioeconomic issues. The seventh domain, ways of coping, contained eight core ideas: humor, positive thinking, withdrawal and isolation, use of faith, maintaining control despite illness, exercise, and information gathering. The eighth domain, disease management, contained two core ideas: lifestyle changes, and education/advocacy. The ninth domain, social support, contained three core ideas: family, support group, and sense of community/cancer survivor community. The tenth domain, processing diagnosis, contained three core ideas: reaction to diagnosis, finding answers, and accepting diagnosis. Finally, the eleventh domain, spirituality, contained two core ideas: prayer and awareness of a higher power.

Table 4

Summary of All Results

Domain	Core Ideas	Frequency
Identity	Perception of self	Typical (7)
	Shifting Roles/Asking for help	Typical (7)
	New Identity	Typical (7)
Biological Changes	Awareness of Body changes	General (10)
	Acceptance of Changes	Typical (6)
Mortality	Awareness of Mortality	Variant (5)
	Unfinished Business	Variant (2)
Changes in relationships	Changes in other's attitudes	Typical (6)
	Dissolution of relationships	Variant (4)
	Dealing with disappointment/lack	Variant (4)

	of support	
Perceptions of the disease	Fatality	Variant (4)
	Myths/Misconceptions	Variant (3)
	Contagiousness	Variant (3)
Issues of Culture	Socioeconomic issues	Variant (4)
	Racial Discrimination	Variant (3)
Ways of coping	Positive Thinking	Typical (8)
	Use of faith	General (10)
	Maintaining control despite illness	Typical (6)
	Withdrawal and isolation	Variant (4)
	Humor	Variant (4)
Disease Management	Education/Advocacy	Typical (8)
	Lifestyle changes	Variant (3)
Social Support	Family	Typical (7)
	Sense of Community/Cancer survivor community	Variant (5)
	Support group	Variant (3)
	Expectations for support	Variant (5)
Processing Diagnosis	Reaction to diagnosis	Variant (4)
	Accepting the diagnosis	Variant (4)
	Finding Answers	Variant (3)

Discussion

The object of this study is to examine the experiences of African American women breast cancer survivors who experienced stigma related to their illness, and the relationship of this experience to their coping strategies. Stigma is a source of stress for its

targets and may have various effects on coping strategies (Miller & Kaiser, 2001). Findings suggest that changes in the attitudes of persons in the patient's immediate environment after their diagnosis of cancer had a negative effect on these women. Eleven out of 13 women who were interviewed admitted feeling stigmatized after being diagnosed with breast cancer. The responses of these 11 participants indicated three broad themes (domains) related to their experiences of stigmatization: changes in their relationships, distorted perceptions about the disease, and issues of culture. This section summarizes the results of the study, discusses the experiences of stigmatization of the participants, explores potential links between the stigmatization experiences and coping strategies, presents limitations of the study, and offers recommendations for future research.

Experiences of Perceived Stigmatization and Impact on Identity

According to the findings the experiences of stigma of the participants had various forms. In a typical statement, one participant reported: "People eventually started looking at you different, like 'she's sick.' You know, that's what they say, 'she's sick.' 'Oh don't do that honey, you're sick.' Or, 'Are you feeling alright today?'" Participants who felt that stigma changed their relationships expressed frustration about others' perception of them as less capable than their healthy counterparts. These findings appear to be consistent with previous research indicating that individuals with cancer experience stigma because others perceive them as having less social value than healthy people (Reidpath et al., 2005).

Another example of women of this study feeling devalued was related to the dissolution of their relationships because of their illness. One participant stated, "It was hard on him. He has this thing he is very positive and that you are beautiful, I don't want to see you suffer.

He tried his best to talk me to a different route and do natural treatments and I would not and that was a deal breaker for him and the relationship resolved.” Additionally, participants experienced avoidance from people that were close to them, as indicated at the dealing with disappointment/lack of support category. These statements seem to show that people from the immediate environment of the participants started distancing themselves when the women’s health started deteriorating and there were visible changes in either their physical appearance or abilities. According to the objectification theory, many women are treated as an object to be valued for its use by others, and to be looked and evaluated on the basis of appearance (Fredrickson & Roberts, 1997). Thus, these findings may suggest a possible objectification of women that diminishes them to their appearance and to adherence to specific gender roles. Instead of seeing these women as people with complex and evolving identities, it appears that some people close to the participants may unintentionally reduce them to their appearance and/or certain abilities related to their pre-established roles. This type of objectification may have a great impact on their sense of power and personal agency.

Participants also expressed their disappointment when people, like family members who they expected to be supportive, avoided them and did not offer their support. One participant for example, stated, “my son, he avoided me. I don’t know what has happened over the years and if the diagnosis has affected him but he has been avoiding me.” These findings appear to be consistent with findings of Wilson and Luker (2006), and may indicate that cancer patients experienced avoidance from others, lack of social support, and social isolation. Findings suggest that participants were reluctant to reach out for help because they were protecting themselves from disappointment. They recognized the

conflict their loved ones experienced between prior perceptions of strength and perceptions of vulnerability due to illness, and that loved ones responded by overprotecting them or by distancing themselves. They also avoided reaching out because they wanted to receive support without having to ask for it. It appears that stigma is perceived as a loss of control of the individual's relationships (either intimate and family relationships or relationships with systemic structures). Loss of control is a common source of psychological distress among patients with chronic illness and their family members and can undermine personal coping (Williams & Koosher, 1998).

The attack on participants' identity as strong and independent seemed to be related to their reluctance to reach out. They felt others no longer recognized their strength and independence after their diagnosis. One participant exemplified this when she said, "Being independent, very self-sufficient, always caring for myself, that part of having to reach out and say hey, I need someone to cook me a meal because I can't lift anything over five pounds..." she shook her head to indicate that she found this very difficult.

Another factor that contributed to participants' experience of stigmatization was the distorted perceptions of the disease. In response to the researcher's questions about their beliefs and the beliefs of their community, they described associations between breast cancer and death, Caucasian women, and contagion. Several participants stated that in their community, "Most people think cancer is death." These findings may explain the additional feelings of marginalization of African American women with breast cancer. Previous research suggests a connection between the perception of contagion and isolation and decreased worth (Reidpath et al., 2005).

Another theme that was found to be related to the experiences of stigmatization was issues related to culture/race. Collectivism—the individual’s concerns about the advancement of the group—is one of the important aspects of African American cultural identity (Akbar 1991; Allen & Bagozzi 2001; Nobles, 1991). It appears that the illness may create a societal-cultural reaction that is alarming for the community and signals the potential loss of one of its members, which in turn may create an internalized reaction of the individual patient, who starts questioning their value as a viable member of the community and of what they can offer to others.

In response to the researcher’s question as to how their experiences as African American women with breast cancer might be different from those of women from other cultures, a small number of participants raised socioeconomic issues or issues of racial discrimination. These participants identified the lack of financial resources and of health insurance as playing a significant role in their treatments. One participant, for example, stated, “Um, I was working a temporary job, I wasn’t insured. And my husband had been laid off as well so neither one of us had insurance and we had three children so when I found this lump under my arm, I didn’t immediately do anything about it.” One participant identified racial discrimination in medical treatment: “Say I was Caucasian. It seems to me that they are treated, even by the medical field, they are jumped on quicker, they are...more adept to get better attention. Their diagnosis, they get diagnosis this day they are getting worked on. You know...it’s like society is saying, ‘Well, we’re gonna hold off and see if your breast cancer progresses.’” Research suggests that White practitioners have a poor understanding of Black women’s beliefs and values about their treatments (Freedman, 1998; Fiscella et al. 2000; Nelson, Smedley, & Stith, 2002). Another

participant, connected being single to race: “I was alone; Black women are alone. I look around and I see White women with their husbands and boyfriends, and I see Black women alone or with some female friend.” Such responses identifying socioeconomic issues and racial discrimination were rare enough for the analysis to identify them as variant, but it is possible that more participants would have identified similar experiences if the interviewer were not Caucasian. As research has revealed, African American women may be distrustful of White women as well as the medical system that they perceive as White (Corbie-Smith, Thomas, & George, 2002). For example, some of the participants may not have disclosed socioeconomic issues because the interviewer was White, non-American, and a researcher, and they may have felt the need to hide socioeconomic issues because of the poverty stigma. Furthermore, one participant stated, “I see no color; cancer sees no color.” Considering that color blindness is found to be related with internalized racism (Neville et al., 2005), the participant may have been unable to identify racial micro-aggressions or discriminatory acts.

Perceived Stigmatization and Sense of Self

In an additional source of perceived stigma, women experienced significant changes in their bodies. During their treatments for breast cancer they became very aware of the changes in their body that they could not prevent, such as hair loss, feeling sick, weight loss, or having scars. One participant reported, “Yeah I had scars, I’m very conscious of my looks. It was a time I lost a lot of weight and I had to buy different size of clothes. And people were like, what does she have? She is losing all this weight, what if she has something else...it also changes your body, I have more allergies, or I had the flu, I never had it before.” At the same time, responses suggest that participants regained a sense of

control by accepting the changes in their bodies, letting go of their remembered body before cancer and embracing their body after the cancer. For example one participant reported, “They were like maybe they will be asymmetrical (referring to her breasts), do you want to put an implant on the other side? And I was no, this side has all its working pieces so I only want to work with this side that was affected.”

Similarly, it appears that women transitioned from having a particular view of themselves (perception of self), to challenging the pre-existing concept of their identities (through shifting roles/asking for help), and to finally developing a new identity. This new identity integrates pre-existing aspects of self with survivorship. Research suggests post-traumatic growth is a common experience of early-stage breast cancer patients (Sears, Stanton, & Danoff-Burg, 2003); active coping accounts for 28% of the variance of growth in breast cancer patients (Bellizi & Blank, 2006). Consistent with prior research, findings of this study appear to indicate that women used a number of coping strategies that contributed to their adjustment to their illness and potentially to the development of their identity as survivors. Specifically, most women in this study talked about active coping strategies such as positive thinking, use of faith, and maintaining control over illness. A third reported using a combination of humor and withdrawal/isolation as a coping strategy. These findings are consistent with prior research on coping with illness (Dunkel-Schetter et al. 1992; Thompson & Kyle, 2000).

Relationship between Stigma and Coping Strategies

These findings suggest complexities that can be related to stigmatization experiences that previous research on coping of breast cancer patients may not have addressed. Much of existing research on coping has little to say about stigma. For

example, past studies have conceptualized positive thinking and withdrawal as avoidant coping strategies that may be related to poor coping (Link, 1987; Taylor & Armor, 1996; Ware & Sherbourne, 1992). However, in the presence of the stigma this study identifies, these coping strategies may be useful, at least for a brief time. Participants' comments suggest that through adapting a positive attitude and actively rejecting negative comments of others or internalized negative thoughts, they regain their power, have hope for the future, and become more motivated to sustain the adversities of their treatment.

Common Coping Strategies

Research suggests that African American women with chronic illness, including breast cancer, frequently cite spirituality and faith as coping strategies (Gullate et al. 2010; Culver et al. 2002; Simon, Crowther, & Higgerson, 2007). More respondents endorsed faith as a coping strategy than any other strategy. Their comments suggest that faith and prayer not only provide hope, but that it also provides a sense of having an ally against the illness and the stigma that is related to it. Participants also seem to regain a sense of control by giving the control of their lives to a higher power. Spirituality is found to play a significant role in the development of post-traumatic growth (e.g., Tedeschi & Calhoun, 2004; Denney, Aten, & Leavell, 2011; Zoellner & Maercker, 2006). Thus, it may be suggested that use of faith may have protected participants from the negative effects of stigma.

Another major coping strategy was “maintaining control despite illness” by maintaining control over their body and their identity. One participant described continuing to work through her treatments, even though the Family Medical Leave Act would have permitted her to take leave from her job as a coping strategy. She also said, “I

advise anyone that is going through chemo, any Black African American lady that has hair: cut it. Cut it off! Cut it! Don't let chemo take it! Have some control—I wanted to have the control, you know? I was not going to let chemo control—my cancer control—who I am.” Considering that power and control are interrelated (Fiske, & Dépret, 1996), comments like these suggest that making certain decisions for themselves and declaring one's worth to society allows participants to reclaim their power.

Another indication of empowerment is related to the domain of disease management, and more specifically to the category that emerged about advocacy. Women talked about their need to help others through sharing their own experience. For example, one woman stated, “After the diagnosis I thought more about how I can share my experience and try to help. I've always had a strong connection to people but through my experience I want people to realize life is shorter than they think and to not take everything for granted. I share the experience with people.” Such comments suggested that by becoming advocates, women felt they connected with the cancer survivor community, fought against the stigma for breast cancer, and reframed their own illness as a “teachable moment” (McBride, Emmons, & Lipkus, 2003; McBride et al., 2008). Almost half of the participants suggested that having a cancer survivor community helped them cope, not only because they received instrumental and emotional help, but also because they felt a sense of belonging and survivorship. The development of a survivor identity, and the need for advocacy may be interrelated; both suggest women's need to give back to the survivor community, and to re-establish their self-concept and social role by finding meaning in their illness (McBride et al, 2003; 2008). These findings seem to be consistent with previous research that indicated breast cancer survivors have a new

philosophy of life, positive views of self, and a renewed sense of relationship with others and “posttraumatic growth” after surviving their illness (Weiss 2004). Research also suggests that membership in a stigmatized group protects individuals’ self-concept (Crocker & Major, 1989). These findings support the analysis that participants develop a shield for their self-concept and create a new meaning and sense of personal identity through their sense of membership in a cancer survivor community.

Research also supports the finding that participants gained support through their family members. Participants talked about the importance of family members providing support and having a positive attitude that communicates caring. Cancer patients frequently turn to family for support (Arora et al. 2007). Furthermore, according to Weiss (2004), marital support and affective family climate is a significant predictor of posttraumatic growth. Additionally, supportive family and friends are associated with a higher level of self-esteem, which in turn was associated with less general distress (Heijer et al., 2012). The emotional and practical availability of family members, thus, may have worked as a protective factor against the stress that stigma creates and contribute to the development of a survivor identity for participants. However, as noted above, many participants—about 50%—experienced disappointment in relation to the support they expected from either their immediate family or the society. These findings suggest the importance of having supportive people or environments that are readily available to provide support.

Summary

The findings of this study shed light on the particular stressors African American women with breast cancer face. They also demonstrate possible interactions between

perceived stigmatization and different coping strategies. Finally, the findings raise more questions about the emotional impact of perceived stigmatization of these women, such as shame, guilt, anger, etc., and the moderating effects of different coping strategies. This study's findings illustrate the variables that contribute to stigmatization of African American women with breast cancer, through decreasing their social power. Future research should further explore the injustices this social group faces and how it affects their social power.

Limitations

Although the researcher took several steps to conduct this project in a trustworthy manner, based on the standards established for CQR, limitations apply. According to Hill et al. (2005), CQR is located in the constructivist philosophy of science with some influences from the post-positivist philosophy. According to constructivism, there are “multiple, equally valid, socially constructed versions of ‘the truth’” (p.197). Thus, by the personalities and interactions of participants, the researcher, and the research team members undoubtedly influenced the insights of this study. In addition, the voluntary nature of the study may impose some selection bias (as we see it from a positivist-post-positivist perspective). Hill et al. (1997) recommended using a random method of sampling in CQR so that unknown biases are not introduced into the research. However, the sampling method employed purposeful recruitment and word of mouth. The majority of participants were recruited through organizations that support women with breast cancer. Thus it is possible that the type of the sample affected the findings indicating that participants especially valued the support from the breast cancer community.

This study is also vulnerable to limitations that are related to qualitative research in general. As Wang (2008) notes, every step in qualitative research is *filtered* through the lenses of the researchers that include values, worldviews, language, and knowledge. Even though the CQR method attempts to control personal biases of the researchers through multiple methods such as journaling and open discussion (Hill et al., 2005), the CQR approach may not have acknowledged and filtered some key biases in this particular study. Furthermore, using a qualitative methodology does not allow any control or manipulation of the variables as in experimental methodology (Wang, 2008), which in turn does not allow any conclusions about cause-effect relationships. Thus, this study cannot draw conclusions about the specific effects of perceived stigmatization on the coping strategies of the participants.

Another limitation of this study pertains to the generalizability and external validity of the results to a broader population of African American women with breast cancer. Due to the small number of participants and the lack of random sampling, the external validity of the study is low. Thus, the results of the study may only be true for the women who participated in the study. Qualitative research also poses challenges in establishing reliability and validity of the approach and of the obtained data, which effects external and internal validity respectively (Wang, 2008). Apart from selection bias, situational variables may constitute a significant threat to external validity and the generalizability of the findings (Shadish, Cook, & Campbell, 2002). For example, variables such as the timing and the location of the interview and the researcher who is asking the questions may affect the findings of this study.

Another limitation of this study was the experience level of the coding team. Even though the coding team and the external auditor had significant clinical experience, they were novices as CQR researchers. Also, the external auditor was not experienced or familiar with the subject of this study—cancer patients. Hill et al. (2005) suggest that external auditors may be less aware of the complexity of the data than internal auditors, who may provide a more holistic and in depth perspective of the data.

Another limitation of this study is related to the homogeneity of the sample. If a sample is less homogeneous the consistency of the results may be affected (Hill et al. 1997). While the sample was diverse in terms of socioeconomic status, time since diagnosis, and chronological age, it was homogeneous in terms of the participants' experience of stigma. It was also homogeneous in that all participants identify as Black women. However, individuals who belong to minority groups have a diverse development of their ethnic/racial identity, which is related to different levels of psychological adjustment (Phinney, 1989). Thus, participants' racial identity may have played a significant role in their experience of stigmatization and their use of different coping strategies.

Implications

The findings of this study suggest that African American women with breast cancer may experience a number of stressors, related not only to their illness but also to certain experiences of stigma. They also suggest that counseling, support groups, and psycho-education about related stressors to these experiences may empower them to overcome their sense of loss of control and social status in the society. Family therapy for families of patients may be helpful with such issues as helping family members to support patients

without becoming overbearing or condescending, and help patients communicate their needs to their family members effectively in a way that feels more comfortable to them.

The study has key implications for oncologists and psycho-oncologists. Psycho-oncologists may create interventions that enhance the self-efficacy of patients and help them restore their sense of control over things through assessing perceived stigmatization. Medical providers who treat African American women should be aware of their own biases and collaborate with patients to ensure their empowerment and avoid discrimination. Additionally, findings suggest that the illness becomes a part of the person's identity that spreads and becomes intertwined with their roles. Psychotherapists may assist patients with breast cancer to explore their new identity and re-integrate it into their pre-existing roles.

Findings also indicate special considerations for social justice advocacy. African American women with breast cancer may experience several forms of discrimination, including not only their illness but also their race/ethnicity. Thus, it is important to consider these stress factors in the development of therapy or psycho-educational programs aimed at supporting African American women with breast cancer.

Future research

Due to the qualitative nature of this study and the small number of the participants, the findings cannot be generalized to the larger population of African American women with breast cancer. Future studies should examine larger samples in order to gain further understanding of the nature and effects of perceived stigmatization in the African American community. In addition, future research should compare the experiences of

women who experience stigma with those who do not, and how these differing experience affect their coping strategies and survivor identity development.

The exploratory nature of this study makes it hard to talk about how certain coping strategies may serve as protective factors against stigma. Future research should use quantitative approaches in order to examine how certain coping strategies may provide a buffer for stigma and possibly enhance the sense of survivorship and posttraumatic growth. The study's findings also raise questions about the emotional impact of stigma, such as anger, shame, and guilt on women African American women survivors.

Furthermore, the current study brought up questions regarding how racial identity development may affect the experiences of the participants. Future research should explore the effects of racial identity on the experience of stigma and coping on African American women with breast cancer.

The experiences of stigma and coping the participants in this study report raises questions about potential differences in the meaning of chronic illness in collectivistic cultures versus individualistic ones. Further research should explore how different cultures understand breast cancer, and the relationship of this meaning to stigmatization of patients.

Finally, this study used a coding team that was diverse in terms of ethnicity, race, and gender in order to analyze and process the interviews of the participants. Scant research has addressed how the diversity or homogeneity of a coding team may affect CQR analysis. Future research should fill this gap.

Conclusion

In summary, the current study uses qualitative methodology in order to explore the experiences of stigmatization of African American women and their coping strategies in depth. Findings of this study indicated that stigma experiences of the participants were related to three different themes: changes in their relationships, distorted perceptions of the disease, and issues of culture. In addition, participants employed a number of different coping strategies in order to cope with the loss of control that resulted from their stigma and their illness, including: active ways of coping, disease management, use of social support, and processing of the diagnosis. Furthermore, findings indicated that participants were able to regain their sense of control and feel empowered, and develop an identity of a survivor despite stigma. Findings of this study also suggest complexities related to coping strategies of cancer patients with breast cancer that experience stigma.

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Appendix A

Initial Letter

Dear potential participant,

My name is Aikaterini (“Katerina”) Psarropoulou, M. A. and I am currently a doctoral student in the Counseling Psychology program at Ball State University, Muncie, Indiana. I am writing to inform you of an opportunity to participate in a research study that involves exploring the experience of African American women diagnosed with breast cancer. To be eligible to participate in the study you must meet the following criteria:

- be an African American female
- be diagnosed with Breast Cancer during the past 3 years
- have no other cancer diagnosis (except non-melanoma skin cancer)
- be ages 25-64 years old
- be fluent in English

The goal of the study is to better understand the experience of African American women living with breast cancer. Participation involves a 45-60 minute audiotaped interview with me at a time and location that is convenient for you.

By participating in this research, you may help others in the future. You will have the opportunity to discuss your personal experience of breast cancer and this information may be especially useful for professionals that work with African American breast cancer patients. You may help these professionals better understand the experience of being an African American woman living with breast cancer. For your participation you will receive a \$20 gift card to Walmart, Target.

If you are interested in participating in the study, please do the following:

1. Read and sign the enclosed **Informed Consent Form**.
2. Answer the questions on the **Contact Form**

If you have any questions regarding the study or the procedures, you may contact me via email at apsarropoulo@bsu.edu or by phone at (765) 702 6581.

I look forward to hearing from you and thanks for considering being a participant in this study!

Principal Investigator:
Katerina Psarropoulou, M. A.
Doctoral Student
Dept. of Counseling Psychology

Faculty Supervisor:
Donald R. Nicholas, Ph. D.
Professor of Psychology- Counseling
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Appendix B

Informed Consent

STUDY TITLE: Perceived Stigmatization and Coping of African American Women with Breast Cancer.

Purpose of the Research:

The purpose of this research is to explore the illness experience of African American women with breast cancer to investigate whether there are any illness-related experiences that may be unique to African American women's experience with this disease. The goal of the study is to advance our understanding of the experience of African American women living with breast cancer.

Rationale:

Few studies to date have specifically explored the personal experience of African American women with breast cancer. This research could be especially useful for health care professionals who work with individuals with breast cancer.

Inclusion Criteria:

To be eligible to participate in this study, you must be an African American female between the ages of 25-65, have been diagnosed with breast cancer (stage 0, I, or stage II) for at least six months to 12 years, and have no other cancer diagnosis (except non-melanoma skin cancer) for the past 1 year. You must not have a diagnosis of metastatic breast cancer (cancer that has spread from the place in which it started to other parts of the body). You must complete the "Self-perceived stigma questionnaire" and you must also be fluent in English.

Explanation of Procedures:

For this study you will initially be asked to sign this informed consent and a contact form and either give them personally back to the principal investigator or return it to the principal investigator "Aikaterini Psarropoulou." This should take approximately 5-10 minutes. A brief (5 minute) phone or in person screening will then be set up with the principal investigator. If after this screening you are found to meet the requirements to be involved in the study, you will participate in a 60-90 minute interview that will be set up at a later time that is convenient for you.

Audio Tapes:

For the purposes of accuracy, with your permission, the interviews will be audio taped. Your names will not be audiotaped. The tapes will be destroyed after they are transcribed.

and the transcriptions will be kept as password protected files on the principal investigator's computer for three years and will then be deleted.

Confidentiality:

Any and all information that is shared with the principal investigator and the research team is private and confidential. In the case that you choose public area for the interview, there may be possible incident disclosure and confidentiality cannot be guaranteed. Names and other identifying information will not be used in the reporting of the data. Written data will be saved on the principal investigator's password protected computer for three years and will then be deleted. Only members of the research team will have access to the data.

Risks:

Participation in the proposed study will include minimal risk to you. Minimal but distressing psychological distress could occur while discussing your personal experience of living with breast cancer. If this were to occur and you wanted to talk to someone about these concerns, you can receive counseling services from the Cancer Counseling Staff at IUBMH by contacting them at 765 751-1449.

Benefits:

The current study may directly benefit you by allowing you to have a safe environment to talk about your experiences (positive and negative) of living with breast cancer. This study could also help researchers better understand the experience of living with breast cancer and help counselors and physicians gain a better understanding of what might facilitate better counselor-patient communication or physician-patient communication.

Compensation:

If you are found eligible after the brief screening questionnaire to participate in the study and begin an interview, you will receive a \$20 gift card to Walmart, or Target. In other words, if at any point after you begin the interview you decide to end or withdraw from participation, you will still receive the gift card.

Withdrawing from the Study:

Participation in this study is completely voluntary and you are free to discontinue participation at any time without question from the investigator. There will be no prejudice for not participating in the study from any agency and/or treatment program (e.g. Little Red Door/Sister's Network) the participants are participating as well. Participants, if they wish, they may pass along information/make others aware of the study. The role of the participants is not to actively recruit any other participants for the present study.

Cost of Participation:

There is no cost to participate in this study.

Questions:

If at any time you have questions regarding your rights as a subject, please contact The Office of Research Integrity, Ball State University, Muncie, IN 47306, (765) 285-5070, irb@bsu.edu.

If at any time you have questions regarding the research, Katerina (Aikaterini) Psarropoulou, M.A., please contact Donald Nicholas, Ph.D. at (765) 285-8040 or dnichola@bsu.edu.

Additionally, you may ask Katerina Psarropoulou, M.A. at (765) 702-6581 or apsarropoulo@bsu.edu any questions before, during, or after the telephone interview. Please also contact Katerina Psarropoulou, M.A. should you have questions to research-related injury.

Do you wish to have the results and explanation of the study sent to you via email at the conclusion of the study? No_____ Yes_____

Consent

I, _____, agree to participate in this research project entitled, “Experience with living with Breast Cancer” I have had the study explained to me and my questions have been answered to my satisfaction. I have read the description of this project and give my consent to participate. I understand that I will receive a copy of this informed consent form to keep for future reference.

To the best of my knowledge, I meet the inclusion criteria for participation (described on the previous page) in this study.

Participant’s Signature

Date

Researcher Contact Information

Principal Investigator:

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Appendix C

Screening Questionnaire

1. Today's date....
2. Date of Breast Cancer diagnosis
3. Age....
4. Has your cancer doctor ever told you that your cancer had returned or spread (Metastatic Cancer)? YES NO

If answer to question 4 is NO

5. Do you know what your stage is? YES NO

If answer to question 5 is NO

6. Have you ever been diagnosed with any other type of cancer? YES NO

If answer to question 6 is YES

7. What type of Cancer?.....
8. How long ago were you diagnosed with this type of Cancer?.....
9. Do you currently have any other type of cancer?

- A. Since the time of your diagnosis with breast cancer did you feel that people treat you differently? YES NO

- B. Do/did you ever feel uncomfortable discussing your diagnosis and/or your symptoms with family members or significant others or others in your community because you were not sure about how they would respond?

YES NO

C. Did you ever have the need to hide your illness from others because you were unsure about how others would respond? YES NO

D. Since the time of your diagnosis with breast cancer did you experience any differences in the way you connect with others?

E. Have you ever felt some kind of stigma because of your breast cancer? YES NO

5. Would you be willing to participate in a 60-90 minute audiotaped interview about your experience of living with breast cancer? YES NO

Inclusion Criteria

Participants will be included in the study if they meet the following criteria:

1. They have been diagnosed with breast cancer 6 months to 12 years ago.
2. They do not have a metastatic cancer.
3. They do not have a diagnosis for a different form of cancer for the past 1 year (other than skin cancer)
4. They answered “yes” to at least one of the A, B, C, D, E questions.

^a THIS QUESTIONNAIRE IS TO BE COMPLETED BY THE RESEARCHER DURING A SCREENING INTERVIEW OF POTENTIAL PARTICIPANTS

Appendix D

Semi-Structured Interview

- What has your experience with breast cancer been like?
- What do your family, friends, and people in your community believe about the impact of breast cancer on someone's life?
- What did breast cancer mean to you before you were diagnosed and after you were diagnosed?
- What was it like when you were undergoing chemo?
- Tell me about the 1st time you remember saying out loud I have cancer and believe it?
- In the initial question, you stated that you (insert question that they said yes to from initial questionnaire), can you tell me more about this?
- How did/do people react to your illness (at time of diagnosis, during treatments, and after finished treatments)?
- How was it for you to tell others you have cancer?
- How did/do other people (family, friends, others) react when you tell/told them about your illness?
- What was your experience with the medical system?
- How connected did/do you feel with other people since your diagnosis?
- How comfortable did/do you feel asking help from others? Please elaborate.
- Did you have any fears after receiving your diagnosis? What were the biggest ones? Do you have those same concerns now, or have they changed?
- How was it for you to have change in your appearance (e.g. scars)?
- Can you talk about any changes that occurred during this journey
- What did you do to get through your illness experience?
- How do you think your experiences (that you just described) affected the way you coped with your illness?
- Are there ways that you coped differently early in your diagnosis VS later
- What is the most salient part of your identity? If you were going to describe yourself, how would you define yourself (3 most important aspects of yourself that influence everything else that you do e.g. race, gender, sexuality)
- How might your experience as an African American woman with breast cancer be different than that of women of other races/ethnicities?
- Are there other coping strategies that you wish you have tried?
- Is there anything that others could do (family, friends, health professionals) that would help you cope with your disease better?
- In what way do you think your life would be different if you had never gone through breast cancer?
- If you could go back to your experience is there anything that you would do differently to cope better with it?

Appendix E

Definition of Terms

Stigma

Stigma is the situation of the individual who is disqualified from full social acceptance (Goffman, 1963).

Coping

To deal with and attempt to overcome problems and difficulties (Webster's Dictionary, 2015).

Breast Cancer

Breast cancer is a cancer that forms in the breast tissues, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk; NCI, 2015).

Cancer Stage

- a) Stage 0 breast cancer: This cancer is non-invasive and small, and it can occur in either one or both breasts. Usually, at this stage the breast tumor cannot be felt but can be detected with mammography. This stage of cancer is curable and five-year survival rates are greater than 95% (Dollinger et al., 1997).
- b) Stage I breast cancer: In this cancer tumors are 2cm or less in size. Standard treatment consists of surgery (lumpectomy or mastectomy) or hormone therapy (Tamoxifen). The survival rate for five years past diagnosis is 85% (Dollinger et al., 1997).

- c) Stage II breast cancer: This cancer consists of either a large tumor (greater than 5 cm) or a tumor of 2-5 cm and positive lymph nodes. Most common treatment approaches include: lumpectomy, mastectomy, chemotherapy, radiation, and Tamoxifen. The five-year survival rate is 66% (Dollinger et al., 1997).
- d) Stage III breast cancer: This cancer consists of a large tumor (over 5 cm). Standard treatment is chemotherapy, radiation, and surgery. The survival rate for stage III is 41% (Dollinger et al., 1997).
- e) Stage IV breast cancer: This is cancer that has metastasized to distant places of the body, such as liver, lung, skin and bones. Standard treatment consists of chemotherapy, radiation, and treatment. The survival rate is 10% (Dollinger et al., 1997).

Mastectomy

Removal of the breast to prevent growth and spread of the tumor (Dollinger et al., 1997).

Lumpectomy

Removal of the lump in the breast and some of the surrounding tissue (Dollinger et al., 1997).

Consensual Qualitative Research (CQR)

Consensual qualitative research (CQR) is a qualitative approach to data analysis that uses open-ended questions in semi-structured data collection techniques (such as interviews), a number of judges throughout the data analysis process (in order to ensure that multiple perspectives will be presented), and consensus between judges about the meaning of the data (Hill et al., 2005; Hill et al., 1997).

Domain

In CQR, a domain is a general topic that aims to group the data (from the interviews) into broad categories (Hill et al., 1997).

Core ideas

In CQR, core ideas represent categories of the domains that aim to summarize the data in fewer words than in the transcription (Hill et al., 1997).

Cross-analysis

In CQR, cross-analysis is the process through which researchers aim to find similarities across transcripts (Hill et al., 1997).

General, Typical, Variant

Core ideas are labeled based on their frequency into general, typical or variant. In CQR, *general* represents a category (a group of data) that is reported by all participants or all but one participant, *typical* represents a category reported by more than half but less than general, and *variant* represents a category reported by at least two cases but less than typical (Hill et al., 1997).

Appendix F

Review of Literature

Cancer and Its Emotional Side Effects

Cancer has a significant impact on patients and their families. Some of the most common psychological responses to a diagnosis of cancer include fear, apprehension, a heightened sense of vulnerability, hope, depression, anxiety, spiritual concerns, confusion, and memory problems (Manos & Christakis, 1985; NCI, 2015; Rossman, 2004). Cancer patients may also face some social stigma because of the illness (Holland & Weiss, 2010). In addition, people with cancer have to manage the physical side effects of the disease and its treatment such as fatigue, pain, nausea and vomiting, hair loss, disrupted sexuality and fertility concerns, nutritional and eating problems, and a number of other physical problems (NCI, 2015; Slovacek et al., 2009).

Significant progress has been made in recent years on research of the psychosocial aspects of cancer, and this research has improved the quality of life of people who experience cancer (Holland & Weis, 2010). However, this has not always been the case. There was a time when many physicians were reluctant to reveal a cancer diagnosis to their patients. Cancer used to be viewed as equivalent to a death sentence, and revealing the diagnosis to the patient was considered harsh and inhumane because the patient would lose any hope and would be unable to cope (Holland & Weis, 2010). The fear of a cancer diagnosis was so significant the family would often hide the diagnosis from others, mainly due to the stigma attached to the diagnosis (Holland & Weiss, 2010). Furthermore, around the world the diagnosis and prognosis of cancer was traditionally withheld from patients because of the fear and the stigma attached to it (Holland, 2004).

Because of this tendency to hide the diagnosis from patients, cancer patients often did not have the opportunity to express their feelings and to talk about how they coped with their illness (Holland, 2004). It appears that there is incongruence between what patients experience and want from the health professional and the health professional's beliefs about how patients deal with their illness. Merluzzi and Martinez Sanchez (1997), in a study that compared perceptions of coping in cancer patients and in nursing personnel, found that patients have a positive perspective about their capacity to cope. The researchers used the Cancer Behavior Inventory (CBI), a measure for self-efficacy and coping with cancer, and they found that patients had higher ratings in coping with side-effects of treatment, maintaining positive attitudes, and seeking social support when compared to the perceptions of the nursing personnel, which indicates that health care providers tend to underestimate the ability of cancer patients to cope with distress. These findings suggest that health professionals need to carefully examine the coping strategies, attitudes, and support network of cancer patients in order to arrive at an accurate understanding of patient adaptation to illness.

Exploring the psychosocial adaptation of patients is a crucial topic in the field of psycho-oncology. Nicholas and Veach (2000) suggested a comprehensive model of psychosocial adaptation of cancer patients, which is seen as an ongoing adjustment process to the plethora of cancer-related stressors that each patient faces. According to this model, psychosocial adaptation is defined as the result of a complex interplay of a variety of factors the patient may or may not be able to control. In addition, there are three components that characterize successful adaptation: a) active involvement in daily life activities, b) ability to minimize possible disruption in different life roles, and c) skill

at regulating emotional distress. Further, Nicholas and Veach (2000) described a dynamic interaction that occurs between three broad classes of variables that include the patient, situation, and life context as indicators of the patient's potential response to a cancer diagnosis. Specifically, the authors suggest the interaction of three classes of variables on psychosocial adaptation: Person-derived variables (past history, demographics, intrapersonal and interpersonal relationships), cancer-derived variables (type, stage, prognosis, clinical course, disability), and life context (culture, health related schema, developmental stage) to regulate the individual's response to cancer-specific stressors. Accurate screening of the patient's psychosocial distress is imperative in order to evaluate the patient's resources and to provide an accurate clinical diagnosis. Examining the aforementioned variables leads to a holistic understanding of the patient's perception of his/her illness, his/her psychosocial adaptation, and perceived social support, which are crucial in the development of the patient's treatment plan (Nicholas & Veach, 2000).

Prevalence of Specific Mental Disorders

Mental disorders are quite prevalent in cancer patients. Massie and Holland (1989) indicated that mental disorders occur in a significant minority of cancer patients. The prevalence of psychiatric disorders in cancer patients is estimated to be high with 47% of cancer patients meeting the criteria for a DSM diagnosis (NCI, 2015). More specifically, of the cancer patients with a psychiatric diagnosis 68% are diagnosed with an adjustment disorder, 13% with depression, and 4% with an anxiety disorder (NCI, 2015). In addition, Post Traumatic Stress Disorder (PTSD) is also another common disorder in cancer patients (Alter, Pelcovitz, & Axelrod, 1996; NCI, 2015).

It is noteworthy to mention that most cancer patients, even though they exhibit symptoms of anxiety, depression, and PTSD, do not meet the criteria for a clinical diagnosis (NCI, 2015). Thus, it is important that mental health professionals distinguish between patients who present with symptoms that occur as a normal reaction to their condition from those with serious mental disorders (NCI, 2015). Also, cancer patients display different levels of emotional distress across different cancer types and based on their gender. Linden, Vodermaier, Mackenzie, and Greig (2012), in a longitudinal study conducted from 2004 to 2009, examined the presence of symptoms versus clinical levels of anxiety and depression. The mean age was 59 years old and 55% were women. The authors found that across cancer types 22.6% of patients endorsed subclinical symptoms of anxiety while 19% showed clinical levels. 16.5% endorsed subclinical depression symptoms and 12.9% demonstrated clinical symptoms of depression. In addition, age and gender appeared to be an important moderator. Women showed significantly higher rates of anxiety and symptoms of depression, and patients younger than 50 years old and women across cancer types showed clinical or subclinical levels of anxiety in over 50% of cases. Thus, it is important that mental health professionals are especially careful when assessing the symptoms of women cancer patients in order to specify whether their symptoms belong to the clinical or subclinical levels of depression and/or anxiety.

Anxiety may affect cancer patients in many ways and may exacerbate symptoms of pain. Symptom exacerbation may then further complicate their cancer treatment. For example, patients with high anxiety levels undergoing cancer treatment may have heightened expectancy of pain or difficulty with sleep; the anxiety may even play a significant role in anticipatory nausea and vomiting (NCI, 2015). It is important that

mental health professionals accurately diagnose patients in order to provide appropriate treatment.

Furthermore, depression may significantly affect the lives of cancer patients. Major depressive disorder (MDD) is significantly higher in a cancer population compared to the general population. Specifically, MDD is estimated to be prevalent in approximately 25% in cancer patients, while it is prevalent in 5-6% of the general population (Massie, 2004). However, it differs in severity according to the type of cancer and cancer treatment (Linden et al., 2012; Massie, 2004). Depression also appears to affect 15% to 25% of cancer patients and is believed to affect men and women at an equal rate (NCI, 2015). Because symptoms of depression are common in cancer patients, it appears that many related myths have developed. Some common myths include: Every cancer patient is depressed, treatments are not helpful, depression in a cancer patient is normal, and all cancer patients face suffering and a painful death (NCI, 2015). While grief and sadness are normal reactions to a cancer diagnosis, patients will often experience these reactions periodically (NCI, 2015). Several factors may contribute to the development of depression in cancer patients.

Pain and other physical symptoms are significant risk factors for depression in cancer patients (Patrick et al., 2003), which in turn may significantly impact their quality of life (Slovacek et al., 2009a). Brown et al. (2012), in a longitudinal single-group cohort study with 329 cancer patients, found a strong correlation between depression and cancer related fatigue. According to the findings, the degree of the association between anxiety and fatigue decreased over time as depression improved, but fatigue continued to be strongly correlated to depression over time. Thus, when a clinician begins to suspect that

a patient is depressed, he or she must thoroughly assess the patient's symptoms.

Symptoms that are mild or subclinical may cause significant distress and may warrant interventions, such as supportive counseling either through a mental health professional or through participation in a self-help group (NCI, 2015).

Post-Traumatic stress disorder (PTSD) is another potential or common mental health problem of cancer patients. The DSM-IV (2000) indicates, "being diagnosed with a life threatening illness" is an example of a traumatic event, which was not included in previous editions. PTSD is estimated to occur in approximately 3% to 4% of early stage cancer patients and in 35% of cancer patients evaluated after treatment (NCI, 2015). In addition, the presence of PTSD symptoms that do not meet the criteria for a clinical diagnosis is estimated to range from 20% in early stage cancer patients to 80% in those with recurrent cancer (NCI, 2015). Cordova et al. (1995), in a study with women diagnosed with breast cancer (early stage), found that women who are younger, from lower Socio-Economic Status (SES), and with fewer years of education are at a higher risk of developing PTSD symptoms. Jacobsen, Sadler, Booth-Jones, et al. (2002) found that women and men who underwent bone marrow transplants showed a significantly higher number of PTSD symptoms when they had lower levels of social support and used avoidance as a coping strategy. Therefore, it appears that patients with certain types of cancer and certain demographic characteristics may be more vulnerable in developing PTSD symptoms related to their cancer diagnosis.

The questions that arise are: how do patients cope with their cancer diagnosis, and how may the patients' coping strategies benefit or hinder their mental health? The coping construct has been extensively examined in the area of health psychology. Failure to cope

with stress may exacerbate illness symptoms; In fact, patients with adequate coping styles show psychological strength and better health when compared to those with poor coping styles (Sachs, 1991). In addition, coping plays a significant role as a moderator between the psychological and physiological predisposition towards illness according to the diathesis stress model (Taylor, 1990). According to the diathesis-stress model, people have different vulnerability levels to mental disorders, which are stimulated by environmental stressors. However, corrective experience can occur and may attenuate the vulnerabilities or certain experiences may cause an increase in vulnerability (Ingram & Price, 2010). Considering the different vulnerability levels of cancer patients in developing mental health problems, it is important that psycho-oncologists examine psychosocial aspects, such as stigmatization of cancer patients. Holland and Weiss (2010) proposed a research model for psycho-oncology in which cancer and related treatments serve as an independent variable and the quality of life, the psychological dimensions, and survival serve as outcome variables. It may be inferred that the psychological dimensions of coping with the diagnosis and the perceived stigma experienced by patients may interfere with the overall “outcome” of patients’ quality of life and survival.

The purpose of this review is to critically examine the coping strategies and perceived stigmatization of cancer patients and to investigate how the experience of stigma may affect the coping strategies of cancer patients.

Theories of Coping

Coping is a psychological construct that has been examined extensively, and many definitions of coping exist. Some of the popular definitions conceptualize coping

either as a stable trait of an individual, as a transaction between the individual and the individual's environment, or as a way of using personal resources in times of stress. This section discusses the literature on theories of coping and is followed by a review of the literature in coping with cancer.

Coping as a Disposition/Trait

The idea that coping is a stable trait has its roots in psychoanalysis and the related notion of defense mechanisms (Parker & Endler, 1992). According to this conceptualization, coping is relatively stable across time, and a person's coping style can be predicted in relation to the way the person reacted in the past (Parker & Endler, 1992). In other words, these theories suggest that coping can be predicted based on the person's personality traits, which are relatively stable across situations and influence the way a person is affected by stressful situations. This approach is also known as the inter-individual approach to coping and refers to the style with which persons cope with different types of problems and situations across time. Also, this approach assumes that coping is relatively independent from the situations encountered and is relatively stable as a "disposition" (Ender, Parker, & Summerfedlt, 1993, p. 389). However, there is disagreement between researchers about the stability of coping. An alternative approach, known as the intra-individual approach, has been proposed. The intra-individual approach to coping examines how a person's behaviors vary in response to different situations and assumes that coping is a dynamic process with little consistency among stressful situations (Ender, Parker, & Summerfedlt, 1993). This approach is also known as a transaction among stressors and the individual.

Coping as a Transaction

According to the transactional model suggested by Lazarus and Folkman (1984), cognitive appraisal is responsible for the coping behaviors of people. Cognitive appraisal is defined as the person's evaluation of the degree to which stressors are threats to their wellbeing and the consideration of appropriate ways to best respond to these stressors (Carver & Sheier, 1994). These cognitive appraisals are divided into two types: primary and secondary appraisals (Lazarus & Folkman, 1984). During the phase of primary appraisal, people evaluate the significance of a stressor or of a situation; during the phase of secondary appraisal, people evaluate their ability to control the stressor and their personal coping resources (Lazarus & Folkman, 1984).

Coping strategies are secondary appraisals and symbolize action tendencies that aim to alter the relationship between the person and the environment (Lazarus, 1991). In other words, coping strategies are cognitive and behavioral efforts that people use in order to cope with environmental demands. However, throughout this process emotion is also intricately involved. Emotions are either focused on the demands of a task (by focusing on altering the relationship between the person and the environment) or are focused on attending to the threat in an emotional way (by thinking about the environment without acting on it). In addition, the transactional model points out that people differ in their appraisal of a situation and thus, what is considered a stressful situation for one person may not be considered as stressful for another person (Carver & Sheier, 1994).

The transactional model indicates that coping is comprised of two dimensions: problem-focused and emotion-focused coping (Lazarus & Folkman, 1984). The dimension of problem-focused coping captures the attempt of the individual to change the

situation and to minimize the potential stressor. In order to achieve that goal, individuals confront the problem and make an action plan. On the other hand, emotion-focused coping captures the effort of the individual to regulate his/her affect or focus as a way to minimize stress. In emotion-focused coping the individual may express his or her emotions related to the problem and seek emotional support from others in order to alleviate the stress that is caused by the problematic event.

Lazarus' model categorizes coping according to how an individual confronts the stressors to either solve the stressor itself or change the way that he or she appraises the stressor emotionally. Endler and Parker (1994) elaborated on dimensions of coping in an attempt to capture the coping construct more thoroughly. Specifically, avoidance coping (e.g. withdrawing oneself from the stressor), direct/indirect coping (e.g. confronting the stressor vs. seeking help from others), and active/passive coping (e.g. taking active steps to remove stressor vs. accepting reality) are discussed in an attempt to better capture both the problem-focused and the emotion-focused styles of coping (Endler & Parker, 1994).

It is important to note that cultural and social factors influence a person's appraisal of a stressful situation (Aldwin, 1994), which may in turn influence the way he or she copes. The transactional model of coping has been criticized for favoring individualistic cultures (Dunahoo, Hobfoll, Monnier, Hulsizer, & Johnson, 1998). According to Jackson, Mackenzie, and Hobfall (2005), the transactional model of coping dichotomizes problem-focused versus emotion-focused coping styles and idealizes problem-focused coping by favoring the notion of independence, personal control, and self-reliance. Furthermore, this dichotomy may undermine support-seeking behavior and disregard the effect of the social and environmental influence on the individual (Jackson

et al., 2005). The social context in which coping develops is likely a very important variable that needs to be examined (Coyne & Smith, 1991). The social environment may play a different role in cultures that are (more) individualistic compared to cultures that are more collectivistic and, consequently, may contribute to the development of different coping styles (Heppner et al., 2005). Thus, constructs (e.g. coping) that have been developed and researched in individualistic cultures may not be appropriate to explain coping styles of people that live in less individualistic cultures (Ægisdóttir, Gerstein & Cinarbas, 2008).

There is significant research suggesting the coping construct may differ significantly across cultures (Heppner et al., 2005; Phillips & Pearson, 1996; Shek & Cheung, 1990). Literature suggests significant differences exist between the coping strategies used by people from individualistic societies versus those used by people of collectivistic societies, with confrontation, active problem solving, and emotional expression being the most common for individualistic societies (Endler & Parker, 1994; Lazarus & Folkman, 1984). Self-regulation and accommodation to the environment have been found to be the most common coping strategies in collectivistic societies (Heppner et al., 2005; Shek & Cheung, 1990). Furthermore, it is suggested that coping behavior is influenced and shaped by cultural and social factors (Aldwin, 1994; Heppner, 2008). Thus, it is important to examine coping in relation to cultural variables that may affect the coping strategies of individuals across different cultures.

In addition to culture, other variables, such as illness, may affect the way people cope. Individuals with chronic illness such as cancer cope in many ways (Manne et al., 2008). The most commonly discussed coping styles involve the use of avoidance,

expressing emotions, and the use of problem-focused or emotion-focused coping strategies (Daunhouer, Crawford, Farmer, & Avis, 2009; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Kvale, 2007). It appears that there is a relationship between the coping strategies that patients use and their adjustment to the illness (Helgeson, Reynolds, & Tomic, 2006; Manne et al., 2008). Thus, it is important to closely examine the role of different coping strategies in the lives of cancer patients.

Coping with Cancer: Specific strategies

Avoidance

Avoidance and cognitive escape, which refers to withdrawing oneself from a problem, is a common coping strategy. The use of avoidance, either by wishing that the problem never occurred or by avoiding taking action regarding the illness, appears to be common in chronic illness, such as cancer. Dunkel-Schetter et al. (1992) investigated the coping patterns of 603 cancer patients. The participants consisted of 78% women, 22% men, and 93% were Caucasian. Participants varied in terms of cancer type and stage, educational background, and income. The Ways of Coping Questionnaire (WOC) (Folkman & Lazarus, 1988) was used in order to assess coping strategies after adapting it for cancer patients. The authors found that certain variables such as personal/environmental variables, appraisal of cancer, medical condition, and emotional distress were related to the coping strategies the cancer patients used. According to their research, five patterns of coping were identified: seeking or using social support, focusing on the positive, distancing, cognitive escape avoidance, and behavioral escape avoidance. There was no evidence supporting the use of a single coping style, and most cancer patients appeared to cope with the stressful aspects of cancer in multiple ways. However,

distancing appeared to be the most common form of coping of the participants. There was also a positive relationship between using or seeking social support and focusing on the positive aspect of the experience (e.g., finding new faith, rediscovering what is important in life, coming out of the experience better than before, etc.). Furthermore, focusing on positive aspects of having cancer was found to be most common in participants who were very religious and who were younger. Focusing on social support was related to higher education levels and higher perceived stress from cancer and worry. Finally, it is noteworthy to mention that cognitive escape-avoidance was related with individuals who possessed less education and higher religiousness.

In a longitudinal study, Felton and Revenson (1984) examined the role of coping and psychological adjustment in a sample of 151 middle-aged and older adults with different types of chronic illnesses. Researchers dichotomized illnesses into two categories based on if they were lowly (cancer and rheumatoid arthritis) or highly controllable disorders (hypertension and diabetes). The sample was primarily comprised of upper middle class, white, married Americans. The WOC and an 8-item scale of acceptance of illness (adjustment) were used in the study, and a cross sectional analysis of coping and adjustment was conducted. Participants were interviewed twice within a seven-month period. According to the findings, coping strategies that appeared to be related to decreased negative affect were those that were related to information seeking and were considered active and confrontive. On the other hand, coping strategies related to wish-fulfilling fantasies involving unrealistic fantasies about how the person would be without the illness were considered avoidant and unrealistic and were associated with increased negative affect. Negative affect was found to be associated with poor general

health and greater disruption of social activities and the individual's belief that they would get sicker easier than others (Hirsch, Mason, & Duberstein, 2009). In contrast, individuals who endorsed positive affect appeared to be less likely to believe they would get sicker than others, were less likely to experience reduction of work or activity time, and were more likely to believe that they are in good health (Hirsch et al., 2009).

Finally, Yang, Brothers, and Anderson (2008), examined coping strategies of 65 women with breast cancer and the relationship of breast cancer to stress. The participants had been diagnosed with cancer 4 months prior to the study. The COPE was used to assess coping strategies. The Quality of Life-Mental Health questionnaire (Ware & Sherbourne, 1992) was used as well. Findings indicated that when stressed women used more engagement coping strategies (changing emotions or thoughts about stressor) than disengagement (denying the stressor happened, drinking) when compared to men. Also, engagement coping strategies were related to higher and lower QOL. These findings suggest that engagement strategies appear to have a beneficial function towards quality of life when compared to disengagement strategies, which involve denial and avoidance of the situation.

Emotional Expressivity

Emotional expressivity is another aspect of coping that has been examined and appears to play a specific role in coping. Kvale (2007), in a qualitative phenomenological study that took place in Norway, investigated coping strategies of cancer inpatients. Twenty patients participated in the study (10 men and 10 women). The participants indicated they needed to have the opportunity to talk about their feelings but wanted to decide when, where, and with whom they were going to talk about their feelings. Also,

the interviews revealed that the patients used cognitive avoidance by avoiding talking about their difficult feelings. The authors suggest this avoidance occurred due to the reported fear of becoming depressed by the subjects.

Furthermore, Anagnostopoulos, Slater, and Fitzsimmons (2010) examined the moderating and mediating role of emotional expressivity and global meaning between intrusive thoughts and psychological adjustment in a sample of 153 breast cancer patients recruited from a general hospital in the capital of Greece. Several self-report measures were administered to the participants: the Life-Attitude Profile-Revised (LAP-R; Reker, 1999), which assessed the personal meaning of life; the Emotional Expressivity Scale (EES; Kring, Smith, & Neal, 1994), which measured the extent to which people outwardly displayed positive and negative emotions through various channels such as facial, vocal or gestural; and the Mini-Mental Adjustment to Cancer (Watchon et al., 1994) scale, which measured coping styles of people with cancer. Their findings indicated that emotional expressivity did not have a moderating or mediating effect on the relationship between intrusive thoughts and psychological adjustment. In other words, emotional expressivity did not appear to facilitate the coping with intrusive thoughts related to cancer. It appears that it is important for patients to have the opportunity to express their emotions. However, emotional expressivity itself may not facilitate coping or adjustment to cancer. Patients may feel better when they know that they have people that they can talk to about their emotions, but the actual deed may not have the expected beneficial results.

Another study that found a relationship among use of emotion-focused techniques and quality of life is that of Daunhouer and colleagues (2009). Researchers examined the

coping strategies of 267 women with breast cancer (mean age 43 years-old). The participants completed surveys within 6 months of diagnosis and then 6 weeks and 6 months later. The WOC for cancer, as adapted by Dunkel-Schetter and colleagues (1992), was used. Findings indicated that coping strategies in these cancer patients changed over time. Specifically, the authors found that social support, spirituality, wishful thinking, and making changes decreased over time but detachment increased. They also found that cognitive restructuring was the most frequent coping strategy used by cancer patients who stayed stable throughout time (in the diagnosis period and throughout different stages of the disease). Furthermore, Dauhauer and colleagues (2009) found that poorer *quality of life* (which refers to psychological well being) was predictive of using coping strategies, such as seeking social support and wishful thinking. The authors suggested that people adapt their coping strategies to the situation they are experiencing. Also, spirituality appears to influence the way that patients cope with the multiple stressful situations they may face.

Spirituality

Spirituality and religion appear to be significant coping mechanisms cancer patients use in order to cope with their disease (Bowie, Curbo, Laveist, Fitzgerald, & Pargament, 2001; Gall, 2000). Holt and colleagues (2011) examined the mediational model of the role of spirituality, religious involvement, and physical/emotional functioning in African-American men and women with cancer. Their findings indicated a positive relationship between religious practices, spiritual well-being and emotional well-being. Also, they confirmed previous findings suggesting that spirituality is related to a positive mental state, which may act as a mediator with health outcomes.

Spirituality may also significantly affect the way patients grow and learn from their disease. Yanez and colleagues (2009) examined the effects of spirituality on the adjustment to having cancer in a large sample of breast cancer patients and survivors. They examined different components of spiritual well-being, such as meaning/peace and faith and their interaction with psychological adjustment. In patients with breast cancer, they found that a higher reported sense of meaning/peace, and/or an increase in meaning/peace over six months predicted a significant decline of symptoms of depression and an increase in vitality. Additionally, this study's findings indicated that cancer-related growth was connected to an increase in faith, suggesting that finding meaning and peace is an influential contributor to better adjustment during the battle with the disease and throughout the survivorship process.

Additionally, spirituality appears to play a significant role in the development of post-traumatic growth, a psychological state of functioning superior to that which existed prior to exposure to trauma (e.g. Tedeschi & Calhoun, 2004; Zoellner & Maercker, 2006). Denney, Atten, and Leavell (2011) investigated post-traumatic spiritual growth in 13 cancer survivors (women and men). They used a qualitative study and the participants ranged in age from 44 to 73 years old. Their findings suggested that participants experienced spiritual growth across the following domains: general spirituality, spiritual development, spiritual social participation, spiritual private practices, spiritual support, spiritual coping, spirituality as motivating forces, spiritual experiences, and spiritual commitment. Also, participants reported believing that their spirituality was strengthened because of their cancer experience and reported seeing themselves as stronger in their faith and more aware of the importance of spirituality in their lives.

Furthermore, spirituality and religiosity may vary depending on culture, and it is important to consider cultural differences when developing programs that aim to improve adjustment to cancer. Lim and Yi (2009) investigated the differences in religiosity, spirituality, and quality of life (QOL) between Korean American and Korean breast and gynecologic cancer survivors and examined the effect of spirituality, religiosity, and social support on QOL. 110 Koreans and 51 Korean Americans participated in the study and completed a mailed questionnaire. According to the author's findings, religiosity, and spirituality were related to some QOL outcomes in significantly differing patterns between the two groups. In this study, Korean Americans reported being significantly more religious than Koreans and also relied more on the support from their church. Additionally, religiosity was positively related to QOL, and this suggests that it may be a vital consideration when developing services for enhancing QOL of cancer survivors from specific cultures.

In addition, another study featuring a non-American population indicates beneficial effects of spirituality in coping with cancer. Harandy and colleagues (2010) conducted in-depth semi-structured interviews with 39 Iranian breast cancer survivors. The authors indicated that spirituality was the primary source of psychological support among participants. Also, almost every participant attributed her cancer to the will of God. Despite this assertion, these individuals were actively engaged with their medical treatment. This result is a surprising contrast to Western cultures in which a belief in an *external health* locus of control appears to decrease participation in cancer screening, detection, and treatment (Harandy et al., 2010). Thus, it is again important to consider

cultural context when developing effective and culturally sensitive health care interventions.

Seeking Social Support

Social support is of importance in coping with cancer not only for cancer patients but also for their significant others. Belcher and colleagues (2011) examined social support processes within the context of the everyday life of couples' cancer experience. They studied the relationship between breast cancer patient reports of receiving support from their spouse/partner (support receipt) and spouse reports of providing support to the patient (support provision) with daily intimacy outcomes. Forty-five women with early stage breast cancer and their spouses independently completed an Internet-based electronic diary assessing support receipt, support provision, and relationship intimacy for seven consecutive evenings shortly after surgery. The research findings indicated that when controlling for patient report of support receipt, spouse report of support provision was uniquely associated with a significant additional increase in feelings of relationship intimacy for patients. Additionally, support receipt and support provision were also found to be beneficial for non-patient spouses' daily feelings of intimacy.

Fitzell and Pakenham (2010) investigated stress and coping predictors in adjustment with cancer in a sample of patient and caregivers. A total of 622 caregivers and their care-recipients completed questionnaires and interviews. Findings suggested that better caregiver adjustment was related to higher social support, lower stress and higher challenge appraisals, and less reliance on avoidance and substance use coping. Also, satisfaction with social support was a stronger predictor of all adjustment outcomes than number of support persons.

Social support such as family emotional support and the opportunity to interact with family members appears to be especially important for the adjustment of women with breast cancer (Bloom, 1986; Bloom & Spiegel, 1984). More recently, Holland and Holahan (2003) examined the relationship between perceived social support and coping to positive adaptation to breast cancer. A total of 56 women, between the ages of 38 and 58 who 1 to 26 months earlier had been diagnosed with Stage I or II breast cancer, participated in the study. The results supported previous findings indicating a significant relationship between perceived social support and psychological adjustment. The authors suggested that having a sense of attachment and social integration are likely important in dealing with breast cancer, as well as important in helping patients reconnect with others after the initial shock of their diagnosis.

Jones, Hadjistavropoulos, and Sherry (2012) investigated the role of socially supportive and unsupportive social interactions in health-related anxiety within a sample of 131 Canadian breast cancer patients utilizing a web-based survey. The results of this study suggested the perceived adequacy of supportive and unsupportive interactions were both significant predictors of overall health related anxiety. Specifically, unsupportive social interactions were the most significant predictor of overall health related anxiety. The authors suggested that when women experience negative social interactions regarding their breast cancer diagnosis, they are more likely to be preoccupied with their body and believe that others are either not responsive to their illness or are not taking their illness concerns seriously. These negative experiences may contribute to the patient's experience of stigmatization.

Stigma of Chronic Illness

Patients with chronic illness have to cope with their illness and overcome physical and psychological symptoms of their illness, and may also be forced to cope with the stigmatization of their condition. Healthy individuals appear to have biases towards people with illness, which affects the way they interact with them (Albrecht, Walker, & Levy, 1982; Field, 1976; Knapp-Oliver & Moyer, 2009; Mosher & Danoff-Burg, 2008). Thus, individuals must not only cope with chronic illness such as cancer but also the social stigma that may be attached to the disease.

A Theoretical Model of Stigma

According to Goffman (1963) stigma is “the situation of the individual who is disqualified from full social acceptance” (Preface). Public stigma has negative consequences for the stigmatized individual and may result in job loss or social isolation (Corrigan & Penn, 1999). Furthermore, Jones and colleagues (1984) indicated that the consequences of stigmatization may be exacerbated by five factors; a) concealability, which refers to whether the condition is obvious or can be hidden, as well as the severity and pattern of the condition over time; b) disruptiveness, which refers to the degree of interference with usual patterns of social interaction; c) aesthetic qualities that refer to how much the condition upsets others by way of the five senses; d) origin, which refers to the perceived cause and degree of responsibility of a person for contracting the illness, and; e) peril, which refers to the amount of fear and danger associated with a person’s illness. In addition, Goffman (1963) indicated that an individual faces discrimination if he or she show a visible sign of difference (e.g. a visible mark on their face), and when the illness is not visible the individual has to decide whether or not they will disclose their condition.

Many kinds of chronic illnesses can meet the criteria that Jones and colleagues (1984) outlined for stigmatization. Illnesses can influence how an individual is both perceived and is actually socially accepted amongst others. Field (1976) indicated that there are four different categories of illnesses (acute, chronic non-stigmatizing, chronic stigmatizing, and mental) that relate to the experience of stigma. The characteristics of illness that distinguish stigmatizing from non-stigmatizing include: a) the degree of difficulty others have in understanding the nature of the symptoms (which can include awareness and education about the illness made available to the social group(s) of which the patient is a member), b) the degree to which illness becomes a central part of identity, and c) the severity and persistence of the social consequences (such as social isolation). In addition, Albrecht and colleagues (1982) indicated that there are two different components that characterize stigmatization in chronic illness: the attribution of responsibility for the stigmatizing illness and the degree to which the illness creates discomfort in social interactions. Also, individuals with chronic illness may be stigmatized because they are perceived as having less social value than healthy people and may be unable to participate in *reciprocal exchange* with other individuals (Reidpath, Chan, Gifford, and Allotey, 2005). Consequently, individuals with cancer are vulnerable to stigma because of their deviance from the healthy population.

Furthermore, healthy individuals may experience particular biases towards people with cancer and consequently that may affect their interactions with them. The visibility of the disease may increase the perception of deviance of patients and the feeling of uneasiness in healthy individuals. Knapp-Oliver and Moyer (2009) examined the visibility and stigmatization of cancer in 299 U.S. undergraduate students. Students were

asked to read and answer questions in response to a vignette featuring an individual with cancer. Researchers controlled the visibility of the condition by administering two different types of vignettes: one describing a patient with a facial melanoma and another one describing a patient as only having cancer. In addition, there was some manipulation of context that included descriptions of people with cancer that wanted to either borrow class notes, or a situation in which a person collapsed and needed help, or a situation in which the person had recently moved to the neighborhood and needed to meet people. Finally, a single item was used to assess students' willingness to help the person. The study's findings indicated that visibility of cancer moderated the effects on the willingness of others to help. Specifically, they found that participants were willing to help a person who wanted to borrow notes or a person who collapsed regardless of the visibility of cancer, but they were less willing to develop a relationship with a cancer patient with visible melanoma who was new to the neighborhood. However, it is important to note that because of the nature of the sample, the results cannot be generalized to the general population, and the findings may be particularly affected by specific characteristics related to the age of undergraduate students.

Furthermore, stigmatization of a patient may be exacerbated because the responsibility for having the disease may be attributed to them. Mosher and Danoff-Burg (2008) investigated the impact of cancer-related stigma in a sample of healthy undergraduate students and community members in the northeastern United States. The participants were randomly assigned to hear an interview (audiotape) of a person with lung cancer. The gender and smoking status (smoker, non-smoker, or unspecified) of the person were manipulated. A total of 289 individuals participated in the study (204

undergraduates and 85 community members). The results of this study suggested women expressed greater pity towards the targeted person when compared to men, and college women reported greater willingness to help the targeted person compared with college men. Furthermore, participants who were exposed to nonsmoking targeted persons expressed lower controllability of the person towards the disease when compared to those exposed to smokers or persons with an unspecified smoking status. Finally, according to the study's findings, participants experienced more anger when the target person they were exposed to was a smoker than when the target person was a nonsmoker or had an unspecified smoking status.

It appears that individuals either feel awkward towards individuals with cancer or believe that individuals with cancer may have responsibility for their disease and consequently do not deserve their empathy. It is reasonable to infer that chronic illness may create significant complications in social interactions. In addition, gender appears to play a significant role in the stigmatization process.

Stigma and Social Support

The social support of a patient may be related to several factors. Females appear to be fortunate when it comes to accessing social support. Bloom and Kessler (1994) investigated the changes in emotional support as a function of time from a surgery in women with breast cancer. Participants of the study were women who went through surgery for different types of diseases: 145 women with breast cancer, 90 women with gallbladder disease, 87 women with benign breast problems, and 90 women that did not go through surgery. Their findings indicated that women with surgery for breast cancer experienced a greater amount of social support compared to women with other types of

surgery during the three months following surgery. However, it is important to note that there is not enough demographic information about the particular sample apart from the age of the women (30-70 years-old). The researchers also indicated that racial minorities were underrepresented in this sample. Consequently, it is important to be careful when interpreting the findings because they may not apply in a different cultural context. The social support for women who are members of minority groups may not be the same because of differences in cultural beliefs about chronic illness.

The interaction between the perceptions of the healthy individuals towards people with cancer and the perceived stigma experience of cancer patients may sabotage the patient's coping resources. Wilson and Luker (2006), in a qualitative study, examined the experience of stigma in cancer patients. Individuals who were interviewed reported that, in regards to their experience with the outside world, they had to cope with avoidance from others, undue admiration, lack of social contact, and social isolation. One of the participants said: "You feel like you've got a (leper's) bell on you and all that...don't mention the word. It's like "Don't mention the war!" (p.1619). The authors explained that the metaphor of war is very common in cancer patients, and they refer to the battle between them and cancer. In addition, the interviews indicated that the disclosure that one has cancer may contribute to stigmatization similar to that experienced by people who have infectious diseases because even the word "cancer" brings images of death and disaster and consequently, provokes existential reflections that can be dreadful to many "normals," who feel awkward when they interact with cancer patients and individuals close to them. Also, another patient said, "it is hurtful to hear people saying that they've fought and got over it. But they all try," indicating (according to the authors) how

distressing it can be for people who are terminally ill because it stigmatizes dying and dead people by implying that they did not try hard enough to fight against the disease and failed to succeed. In addition, the authors indicated that by talking about their illness the patients became more capable of managing their emotions.

In addition, Heijer and colleagues (2012) examined the impact of both personal and social resources to psychological distress and the associations between social resources and psychological distress in a sample of 222 women with a high risk for breast cancer. Findings indicated that supportive family and friends was associated with a higher level of self-esteem, which in turn was associated with less general distress. Also, communication regarding cancer within the nuclear family was negatively related to feelings of stigmatization, which in turn was associated with less general as well as breast cancer specific distress. Additionally, open communication within the family was associated with a reduced sense of vulnerability.

The experience of going through cancer can be especially traumatizing for patients. They may not only perceive the changes in behaviors of people in their immediate environment but may also have to deal with common misconceptions about their disease. Even if social support is available to them, they may not be willing to use it for various reasons. The question that remains unanswered is, despite the availability of social support, how much do individuals with cancer actually use their social resources? It is important to understand how people cope with their stigma in order to further understand their adjustment to their condition.

Perceived Stigma and Adjustment to Disease

Having a life threatening and stigmatizing disease may affect many different aspects of the individual's life. Patients may reconsider their personal identity and consequently change the way they view themselves. Coping with illness and with the stigma that is attached to it may contribute to the development of the person's new identity as an individual with an illness. Rossman (2004) interviewed men and women, diagnosed with either breast or lung cancer or with chemotherapy induced alopecia. Rossman examined the perceived stigma these subjects experienced. The study was of an exploratory, qualitative nature. Rossman found that the participants experienced various types of difficulties in their everyday life. Most women in the study expressed that they experienced hair loss as a confrontation of a fatal illness, and in order to cope they engaged in various covering techniques, such as wearing a wig. On the other hand, men and some women accepted their baldness as a logical consequence of their treatment. Men did not wear wigs and women used to wear wigs only in certain occasions (mostly in order to protect their family members) as a way of rendering their stigma banal and developing the new identity of a cancer patient.

In addition, stigma may inflate psychological distress, which in turn sabotages psychological adjustment. Taft, Keefer, Leonard, & Nealon-Woods (2009) examined the perceived stigma of people with inflammatory bowel disease. Taft and colleagues (2009) found that 84% of the participants experienced stigma regarding their conditions, and the perceived stigma significantly predicted somatization, depression, and anxiety. In addition, results indicated a positive relationship between higher levels of perceived stigma with greater disease flare-ups, which increased the participant's ability to conceal the disease, and higher perceived stigma with overall poorer health related quality of life.

In addition to leading to psychological problems such as depression, stigmatization affects a person's quality of life. A single longitudinal study examined the relationship between stigma and quality of life. Greeff, Uys, and Wantland (2010) conducted a longitudinal study in which five African countries participated and followed 1457 HIV positive patients for a period of one year. Seventy-two percent of the participants were women and the mean age was 36.8 years. Greeff and colleagues (2010) found that as stigma increased over time, life satisfaction decreased. Also, the factors that had a positive influence on life satisfaction were: taking medical treatment, having reduced symptom intensity, and disclosure of the disease to a friend.

Perceived Stigma Discrimination and Self-Blame

Apart from the problems that stigmatization can cause to the social support of the person, it may also affect the quality of their medical care. In a study that examined the social stigma of lung cancer, Chapple and colleagues (2004) interviewed people diagnosed with the disease to ask questions about their experiences with doctors. Participants, both smokers and nonsmokers, indicated doctors treated them unfairly and they felt unjustly blamed for their illness. One of the participants said that when he asked his doctor what he believed was the cause of his cancer the doctor laughed and said that it was obviously due to smoking. However, the patient had never smoked in his life. Another participant, who was a smoker, indicated his frustration was because when he went to the doctor with phlegm and intense cough, the doctor asked him if he smoked and sent him home with cough drops instead of offering a hospital visit. Raleigh (2010) indicated that psychological aspects of lung cancer result from the social stigma that is attached to it. Guilt is a very common consequence. Smokers experience guilt for having

engaged in a behavior that increased their risk for cancer, while non-smokers wonder about what they have done to deserve the disease (Raleigh, 2010). These studies indicate lung cancer can be particularly stigmatizing for patients. It is important to further investigate the consequences of such discrimination in the coping strategies related to seeking palliative care. Studies are also needed to examine how much stigma affects the psychological health of patients and the way they cope with it.

Stigmatization may significantly affect the psychological adjustment of patients and may contribute to the exacerbation of psychological distress. Else-Quest and colleagues (2009) examined the perceived stigma in patients with lung, breast, and prostate cancer. Participants were recruited from the University of Wisconsin Comprehensive Cancer Center. A total of 172 cancer patients participated in the study. Participants were administered a battery of self-report measures that assessed self-blame, self-esteem, anxiety, anger, depressed affect and causal attributions. Also, a single item assessing perceived stigma was added to the battery. Findings indicated that self-blame was linked to lower psychological adjustment to all three types of cancer. Also, results indicated that self-blame mediated the relationship between perceived stigma and psychological adjustment and explained a greater percentage of variance in patients with lung cancer that showed higher perceived stigma compared to breast and prostate cancer.

Fife and Wright (2000), in their study with 76 cancer patients and 130 AIDS/HIV patients, examined the impact of stigma (such as social rejection or shame and isolation) on patients' self-esteem, body image, and mastery. While individuals with AIDS/HIV reported higher feelings of stigmatization than those with cancer, the type of illness did not appear to affect any dimension of self-perception. Fife and Wright (2000) found that

decreased functional health status was related to greater stigmatization. Fife and Wright's findings suggested greater illness degree was associated with greater difficulty in concealing the illness and greater illness degree also indicated less opportunity of patients to participate in normal activities. Their findings also suggested that greater illness degree had an overall negative association with general functioning.

Stigma and Coping with Chronic Illness

Individuals with chronic illness appear to feel stigmatized and that stigmatization affects their quality of life, adjustment to their illness, and their psychological distress (Greeff et al., 2010; Raleigh, 2010; Rossman, 2004; Taft et al., 2009). Better quality of life and better adjustment to the disease appear to be related to the use of various coping strategies (Dunkel-Schetter et al., 1992; Felton & Revenson, 1984; Hirsch et al., 2009). However, how does stigma affect the coping strategies patients use and therefore their quality of life? Also, how does stigma function within different cultures in the way that it interacts with coping styles of people?

Individuals who experience stigma for their illness may adopt coping strategies such as secrecy and social withdrawal that in turn may result in poor quality of life (Link, 1987). In his review about the social support of the patient with cancer, Krishnasamy (1996) highlighted that past research indicated the benefits of social support to cancer patients and their adjustment to the stress of their illness. He also suggested that cancer patients have intense fears of obtaining social support because of the stigma associated with the disease. Consequently, people with higher perceptions of stigma for their condition may become isolated and have restricted coping resources compared to those who feel less stigmatized.

The perceived stigma of people with illness may also impede their willingness to seek professional help. Matthews and colleagues (2003) indicated that despite the significant contribution of psychology to the treatment of cancer, there is a significant stigma barrier in the psychological help seeking behavior of cancer patients. Specifically, these authors indicated that cancer patients are not aware of the benefits of psychotherapy and how it can improve their coping ability; moreover, cancer patients may see mental health treatment through a negative lens and as ineffective. In this way their social support resources can be even more restricted, and they may not be able to normalize their experience.

It is apparent that there is a gap in the literature regarding the relationship between perceived stigmas and coping styles of cancer patients. Few studies have investigated both variables within the same study. Joachim and Acorn (2000), in their review about the experience of living with chronic illness, indicated that overall, researchers tend to examine the chronic illness experience either from the perspective of patients who experience stigma or they do not consider the impact of stigma at all. Specifically, Joachim and Acorn (2000) noted that studying chronic illness through the lens of stigma contributes to our understanding of how a person with a particular condition is treated by society at a particular point in time and contributes to the examination of the challenging social context in which a person with chronic illness lives. When coping with chronic illness is examined without consideration of the impact of stigma, the importance of the broader social context is missed. Most research has simply attempted to understand how people's coping strategies result in overall adaptation. The lack of research that includes both stigma and coping may miss the impact of stigma—an important variable when

considering the broader social context. Thus, it is important to examine persons' experiences with a chronic illness by considering both variables: stigma and coping.

Furthermore, the majority of the stigma literature in chronic illness comes from individualistic cultures, and there is a lack of literature examining how people with chronic illness face stigmatization in societies that are more communal/collectivistic.

Individuals with chronic illness, such as cancer, do not live in a vacuum. On the contrary they are members of a system they interact with, and they develop strategies to cope not only with their illness and its threats but also with their environment. An investigation of the experience of stigma and the coping strategies people use in order to adjust to their illness may contribute to the understanding of chronic illness within the social context that exists. Such investigation may facilitate the development of legislative and educational advances that will enhance the lives of patients (Joachim & Acorn, 2000, p.45).

Cancer and African Americans

There is increased interest in researching the screening attitudes of African Americans. In a qualitative study, Peek, and colleagues (2008) examined the effects of fear and fatalism in screening of 29 African American Women. According to their findings, women of that group questioned physicians' competence and ethics, and they also had fatalistic beliefs about cancer. Specifically, these women feared being subjected to an unnecessary mastectomy either because of doctors' errors or due to unethical experimentation. It is important to note here that data does exist showing that African American women may be less likely to receive lumpectomy (breast-conserving therapy) than mastectomy, compared to Caucasian women (Nattinger, Gottlieb, Veum, Yahnke, &

Goodwin, 1992). In addition, Peek and colleagues (2008) indicated that some of the fear of screening arose from the fear of mammography itself, due to either lack of accurate information or miscommunication between women and the medical personnel.

Furthermore, delay in seeking medical care has been found to be a significant contributing factor late-stage breast cancer diagnoses in African American women (Bibb 2001; Burgess, Ramierz, Richards, & Love, 1998). Spirituality appears to be a factor that may interfere with screening behaviors and seeking medical care. Gullate and colleagues (2010) examined the role of spirituality in seeking medical care in a sample of 129 African American women with breast cancer. Findings indicated that the median delay from the time of self-detection of a breast symptom to seeking medical care was 5.5 months. Also, women who were single, less educated, and *talked to God* as a way to cope and as a response to their breast symptoms, were significantly more likely to postpone medical care seeking, and as a result more likely to present with a later stage breast cancer than women who sought medical care within 3 months of symptom discovery. Thus it appears that, at times, religiosity may hinder African American women from taking active steps toward cancer screening and therapy.

Culver, Arena, Antoni, and Carver, (2002) examined coping and distress in a sample of Hispanic, African American, and Caucasian breast cancer patients. The participants were comprised of 131 patients with stage I and stage II breast cancer. In order to assess different coping strategies, such as religious coping, venting, and use of humor, the researchers used the brief COPE (Carver, 1997; Carver et al., 1989), and the Center for Epidemiology Studies Depression Scale (CES-D). Also, in order to further examine distress, they used a series of mood adjectives (e.g. tense, nervous, hopeless,

unhappy) reflecting anxiety and depression. Participants indicated the extent to which they had each feeling (e.g. tense, unhappy), using response choices ranging from 1 ('not at all') to 5 ('a lot'). In regards to coping, findings indicated that African American and Hispanic women used more religious coping and less use of humor than Caucasian women. Also, African Americans reported less use of venting (free expression of a strong emotion) than Caucasians and Hispanics. In regard to distress, their findings indicated that African American women showed lower distress levels compared to Caucasians and lower depressive symptoms than both Caucasians and Hispanics. The authors suggest that higher levels of stoicism are correlated with lower levels of distress in this cultural group.

In a follow up cross-sectional study, Culver, Arena, Antoni, and Carver (2004) further examined coping differences between African American, Hispanic, and Caucasian women in a sample of 236 breast cancer patients. Participants were middle class, and they were matched in terms of education and distress. The most salient difference in this group is that African American and Caucasian women do not use venting as much as Hispanic women. Also, this study replicated the previous findings of Culver et al. (2002), indicating higher use of spirituality in minority groups when compared to Caucasians.

Simon and colleagues (2007) examined the use of spirituality as a coping strategy in a qualitative study with 18 African American women. The study's results suggested that spirituality was a significant component in their coping from diagnosis to survivorship. Specifically, some of the participants indicated that their faith in God helped them accept their diagnosis, decide their type of treatment, cope with the effects of their treatment, find life meaning and the will to live throughout their treatment, and find hope. Also, during survivorship, they indicated that they saw their faith as a reason for

survivorship and thus as a source of strength, and their spirituality helped them cope with the possibility of the recurrence of the disease. Overall, findings suggested that African American women use spirituality as a main coping strategy throughout their battle with cancer from the point of diagnosis, to treatment, and to survivorship.

Im, Lim, Clark, and Chee (2008) explored the pain experiences of African American women with cancer through a qualitative study. Several topics emerged during the analysis of the data: a) cancer represents a challenge in life, b) cancer is a death sentence with no hope for survival, c) cancer is a challenge that God allowed them to have in order to test their faith, and d) cancer pain is a stigmatized experience and something to be ashamed of and thus, something that they keep for themselves and do not share with others. In addition, strength and stoicism emerged as a main theme of the participants. Participants reported they had to be stoic toward their pain because they were raised to be strong and cancer creates a change in perspectives. In other words, according to this study's findings, African American women's pain experience is unique, and while it can be very distressing, it may also provide a unique post-traumatic experience. According to the author, African American women see pain expression as a sign of weakness, and weakness is not viewed well in African American culture. These findings support Guidry, Matthews-Juarez, and Copeland (2003) suggestion that African American women place more emphasis on the needs of their families rather than themselves. Thus it is possible that societal/cultural values of the African American community make it more difficult for women to share their pain and possibly the severity of their diagnosis with other members of the family or their community for fear that they may be seen as inadequate for their roles.

Heiney and colleagues (2011) examined the theory of community connection in African American women with breast cancer. Community connection is defined as relationships that are supportive and are outside of extended family and within communities in which women live, such as churches and sororities. Findings indicated that community connection was associated with cancer stigma, stress, and spirituality, but not associated with fatalism. Also, fear and isolation were mediating the aforementioned relationship.

Even though several studies aimed to examine the experience of African American women with cancer and breast cancer specifically, it appears that there is a lack of literature that explores the perceived stigmatization of African American breast cancer patients and how it may affect the coping strategies of these women. In addition, even though several studies examined the coping strategies of cancer patients and women with breast cancer specifically (Culver et al., 2002; Culver et al., 2004; Daunhouer et al., 2009; Yang et al., 2008) they used, to a great extent, quantitative methods and questionnaires that have been standardized primarily with Caucasian participants (e.g. COPE; WOC; WOC-CA). The use of measures with low cultural sensitivity may lead to misinterpretation and misconstruction of the experiences of certain cultural groups (Ægisdóttir et al., 2008) such as Black women (Few, Stephens, & Rouse-Arnett, 2003). Specifically, there are a number of problems with past research with Black women (Few et al., 2003). Some of these problems include the following: a) the main focus on Black family life tends to be deviance and negative outcomes, b) the experience of Blacks tends to be presented in terms of their difference from Whites, c) Black family life is usually represented through comparative quantitative data collected mostly from Whites, d)

quantitative findings about the effects of race are, for the most part, bi-products of statistical controls for race or ethnicity, and e) researchers have used traditional theories that do not reflect the holistic experience of Black women. Thus the need for a culturally sensitive theoretical framework is imperative for the empirical research of African American women. The bulk of the empirical research on African American women with cancer is characterized by the lack of a theoretical framework that allows an in depth examination of the contextual, cultural, and gender related variables that contribute to the development of their unique experiences.

Feminist Theory and Research

Research on topics of relevance to women often does not take into consideration the systemic, structural, or politicized theoretical framings (Zubriggen & Capdevilla, 2010). The feminist perspective can guide research, both quantitative and/or qualitative, and may provide a unified framework for analysis (Tong, 1998). This framework provides pluralistic perspectives including liberal, essentialist, radical, socialist, Marxist, and post-modern feminism (Tong, 1998). Sullivan (1992) pointed out that taking gender as a starting point of inquiry is a necessary but not a sufficient condition of feminist research. Further, Sullivan indicated that feminism's ideological goal is to change patriarchal assumptions and practices that misrepresent or hide women's experiences. Despite the variances in perspectives, the underlying commonality lies in the fact that feminist perspective prioritizes research participant's own views, opinions, perspectives, experiences and interests, and emphasizes minimizing the distance between research participants and researcher by recognizing a mutual creation of the data (Hall & Stevens, 1991; Wuest, 1993). In addition, the feminist theory highlights the contexts of people's

lives that may influence the research phenomenon itself and the cultural and societal views of the phenomenon (Eichler & McLaren, 1988). Furthermore, feminism underscores the examination of diverse ethnic, racial, and gender related variables and the way these variables of the individuals interact with the environment (Campbell, 2002; Eichler & McLaren, 1988). Addressing diversity in research is key in examining disparities in different settings such as the health care system. Stern (1996) pointed out the disparities in health care between women and men. Specifically, Stern indicated five problems in women's health that stem from three primary *female issues*: reproduction and fertility, having less power than men, and aging. These problems are a) valuing young girls for their beauty instead of their intelligence; b) valuing women as reproducers and sex objects; c) discounting the chronic illness that comes with living a long time and taking care of young children, parents, and elderly spouses-even when the caretaker herself is ill; d) being poor; and e) being valued less with increasing age (p.153).

Feminist theory and research aims to address these disparities and to empower women by examining their experiences and changing the status quo in order to address their needs. Addison and McGee (1999) indicated that there are two basic principles of feminist empirical research: a) the starting point of feminist research is one's political commitments, and b) the goal of feminist empirical research is to produce social and individual change. Addison and McGee (1999) clarify that when they talk about having as a starting point one's political commitments, they mean that empirical research is never neutral and that researcher's political commitments in relation to the research should be explicitly acknowledged. The methodology and choice of participants are always political acts with social implications (Addison & McGee, 1999). Similarly, they

point out that the claim that the goal of empirical research is to create social and individual change implies that participants have a voice in the development of the research and thus feminist research is done for and with participants. In addition, Hall and Stevens (1991) indicated three basic tenets inherent in all feminist theories: a) a valuing of women and their experiences, needs and ideas; b) a recognition of oppressive conditions in women's lives; and c) a desire to bring about social change through political action and criticism of the oppressive societal values.

Finally, the feminist perspective sees bias as an almost inevitable part of the process and highlights that researchers should be reflective about their own views during the research process (Olesen, 1994). The biases can be valuable resources if researchers are able to reflect on their own views throughout the research process and see how their views may affect their research process and thus the research phenomenon (Olesen, 1994).

The goal of feminist research is to overcome social inequalities and gender injustice (Undurraga, 2010) and is concerned with asymmetrical power relationships, including research relationships that involve a power differential between the researcher and the research participant (Charles, 1996; Undurraga, 2010). Feminism provides an egalitarian model for research, where the researcher's and the participant's relationship is non-hierarchical, non-exploitative, non-manipulative, and non-authoritarian (Maynard, 1994; Reinhartz, 1983). Further, it is important to note that what differentiates feminist research is not the use of a particular method but the way this method is used (Letherby, 2003). There is no single way of doing feminist research or one method attributed to it, and both quantitative and qualitative methods can be feminist or non-feminist, depending

on the ways that they are theorized or practiced (Letherby, 2003). Historically, feminists have used various methods in order to understand women's lives. These methods include interviews, focus groups, life histories, and conversational analysis (diaries, letters, questionnaires and statistics, and participants and non-participant observation) (Letherby, 2003). Historically, most feminist research has used the qualitative methodology in order to examine in depth the realities of individuals. More specifically, Black feminism has used qualitative methods of inquiry in order to focus on individual functioning, goals, and meaning within Black and female realities (Few et al., 2003).

Proposed Methods: Qualitative Research

Limitations in the prior literature result in a number of unanswered questions regarding the nature of cancer-related stigma in the African American breast cancer community. Do most African American women experience stigma when diagnosed with cancer? If so, in what form does the stigma appear (e.g., cancer as a punishment from God, cancer as a "death sentence," etc.), and how does the experienced stigma affect coping? In-depth, semi-structured interviews are needed with African American women with breast cancer in order to examine these questions. This calls for a qualitative research design.

Qualitative research has much to offer to counseling and psychotherapy in terms of generating new understandings in complicated phenomena by providing a vivid and full description in the natural language of the phenomenon under study (McLeod, 2011; Miles & Huberman, 1994). Rather than being constricted by pre-determined constructs, qualitative researchers explore phenomena as they naturally occur thus allowing researchers to describe various phenomena in depth (Hill et al., 1997). Qualitative

methodology is used to further understand a phenomenon of interest and allows for the importance of context to be considered. It also provides an in-depth understanding of the individuals' created meaning of their lives and experiences (Wang, 2008).

Qualitative Method: Approach to Data Analysis

The qualitative approach that will be used for the present study will be phenomenological (Creswell, Hanson, Plano-Clark, & Morales, 2007). The phenomenological approach aims to *describe* a particular segment of social reality, and once the description is accomplished, it can be analyzed in terms of patterns and themes, or be interpreted in relation to its wider meaning and significance (Creswell et al., 2007; McLeod, 2011). As a result, the phenomenological approach to qualitative research aims to better understand the meaning of the particular phenomenon, persuade others of the credibility of the conclusions arising from the study, and contribute to the creation of social justice (McLeod, 2011). In order to do so a rigorous data analysis will be used.

Consensual qualitative research (CQR) is a rigorous, fairly newly developed approach that uses: a) open-ended questions in semi-structured data collection techniques (such as interviews); b) a number of judges throughout the data analysis process (in order to ensure that multiple perspectives will be presented); c) consensus between judges about the meaning of the data; d) one auditor that checks the work of the judges and minimizes the effects of groupthink; and e) domains, core ideas, and cross-analysis in the data analysis (Hill et al., 2005).

At this point it is important to discuss the nature of the philosophy of phenomenology. Ponterotto's five constructs, ontology (view of the nature of reality), epistemology (view of the relationship between the researcher and the participants),

axiology (role values within the research process), rhetorical structure (language used to present the procedures and results of the research to the intended audience), and methods, will be discussed in order to better understand phenomenology. With respect to ontology, CQR is constructivist, which means individuals construct their own reality; thus, there are multiple equally valid, socially constructed versions of truth (Hill et al., 2005). In terms of epistemology, CQR is constructivist with some post-positivist elements; the researcher and the participant have mutual influence on each other, and the researchers role is to be a *trustworthy reporter* who aims to reveal the participant's beliefs through the use of a structured protocol across participants in order to acquire consistent areas of information (post-positivist element; Hill et al., 2005). With regard to axiology, CQR lies between constructivism and post-positivism; the biases of the researcher are seen as inevitable and should be discussed in depth (constructivist) in order to avoid undue influence on research results (post-positivism; Hill et al., 2005). Also, it is important to minimize as much as possible the idiosyncratic impact of the interviewers by using a consistent interview protocol and encouraging interviewers to be aware of their own biases (Hill et al., 2005). With respect to rhetorical structure, CQR is somewhat post-positivist in that the data is reported in third person, attempts to be objective, summarizes the participant's words, remains close to the data (rather than making major interpretations), and trying to find themes across participants (Hill et al., 2005). With regard to methods, CQR is constructivist as it relies on naturalistic, interactive data collection methods (Hill et al., 2005). Furthermore, in CQR, it is important that the researcher discusses his/her own biases and potential influence on the data (Hill et al.,

1997). The biases of the investigator will be analytically discussed in the methods section.

Qualitative research aims to enrich empirical data by highlighting the meanings behind the numbers and addressing cultural distinctions between and within groups (Few et al., 2003). Also, it is important for the researcher to ask what role qualitative research could have in advancing the field of counseling psychology (Haverkamp, Morrow, & Ponterotto, 2005). A qualitative approach to investigating the reasons for participation in a behavior (e.g. coping strategies), may help lead to better developed individual interventions for African American women with breast cancer. It may also help improve communication between patients and health professionals. Without knowing the reasons behind a coping behavior, it may be challenging to develop individualized interventions and help patients develop healthy coping strategies.

Research Paradigm

A paradigm is a philosophical/theoretical framework within a discipline that aims to help one understand his/her own philosophy of science as one goes through his or her own research process (Ponterotto, 2005). The research paradigm that was used for this study was based on both post-positivist and constructivist philosophies. The principle investigator of the current study has been trained in both quantitative approaches (post-positivist) and a feminist perspective (constructivist), which were both influential in the construction and analysis of the current study. The ontology, epistemology, and axiology of this study were influenced by both of these perspectives, with greater influence coming from constructivism. This philosophy is consistent with the underpinnings of CQR,

which fall within the constructivist-post-positivist continuum, with the constructivist philosophy being somewhat of stronger influence (Hill et al., 2005; Hill et al., 1997).

Ontology

Strong constructivist influences due to a feminist perspective and a belief in the existence of multiple realities (Ponterotto, 2005) formed the philosophical underpinnings of this study. In addition, the belief that people perceive the world in multiple ways, that are equally valid, was an important consideration when designing this study. In the CQR, team members must come to a consensus of opinions, which is an expression of validation of multiple realities (Hill et al., 2005). Although some argue that finding consensus in a research team may significantly compromise the individual realities (i.e., Ponterotto, 2005), coming to a team consensus can also be seen as another valid reality; the reality of the team and but not necessarily of the participants (Hill et al., 2005). Throughout the process of arriving at a consensus, team members interact with each other and, in this way, affect their realities through different opinions, suggestions, and consensual conclusions.

Epistemology

Like the research paradigm and ontology of the study, the relationship between the participants and researcher was also influenced by both constructivist and post-positivist philosophies. The current study was conducted based upon the idea that the researcher and participant influence each other to a certain extent (constructivist), and the researchers role is to be a “trustworthy reporter” that aims to reveal the participant’s beliefs through the use of a structured protocol across participants in order to acquire consistent information (post-positivist; Hill et al., 2005). Since minimal probing was used

and a set of previously constructed interview questions were used with each participant, the researcher and participant mutually did not influence each other to an extent that could compromise the integrity of the data collected (Hill et al., 2005).

Axiology

Researcher biases were addressed from both constructivist and post-positivist philosophical perspectives. According to a constructivist perspective, the researcher biases are inevitable and should be discussed in depth in order to avoid unduly influencing results (Hill et al., 2005). In addition, Hill and colleagues (2005) stress the importance of minimizing the idiosyncratic impact of the interviewers by using a consistent interview protocol and encouraging interviewers to be aware of their own biases. Biases cannot be eliminated from the process but can be acknowledged and openly discussed in order to inform the research process (Hill et al., 2005).

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